Perceptions of post-TBI healthcare experiences by individuals with traumatic brain injury

By

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Purpose: The purpose of this study was to investigate the healthcare perceptions for individuals with traumatic brain injury (TBI) across the continuum of care, including during the acute, transitional, and chronic phases of recovery. While previous researchers have investigated perceptions of individuals with TBI in the acute and transitional phase, there is a paucity of research specifically evaluating the chronic phase of recovery (Manskow et al., 2018; Turner, Fleming, Ownsworth, & Cornwell, 2008). These perceptions are especially critical to evaluate given prior research indicating personal attitudes may have the potential to impact functional outcomes (Sherer et al., 2014).

Methods: This was a two-part study consisting of an online Qualtrics-based survey and follow-up qualitative interviews. Part one: Sixty-four participants with TBI were recruited from community-based brain injury groups for the survey portion. Out of 818 community-group leaders who received invitations, 74 responded and distributed surveys to their groups. Eleven online Facebook group administrators were contacted but only one responded, agreeing to post to their 29,000 member site. The online survey included questions related to demographics, perceptions of healthcare, follow-up services, and satisfaction with service delivery. Perceptions of healthcare experiences were measured through a modified Consultation and Relational Empathy (CARE) measure (Mercer, Maxwell, Heaney, & Watt, 2004), the modified CARE questionnaire for persons with TBI (mCARE-TBI; Spreitzer & Hoepner, 2019). Content validity of the mCARE-TBI was addressed by a panel of experts in TBI rehabilitation and scale development, while face validity was addressed through a pilot focus group of individuals with TBI. After
completing the survey, participants were given the opportunity to engage in a qualitative interview. **Part two:** of the investigation followed an interpretive phenomenological approach to capture in-depth healthcare perceptions and experiences of five individuals recovering from mild TBIs.

**Results:** The survey provided a great deal of demographic information, including severity of TBI, length of stay and rehabilitation, post-TBI employment, and other racial/cultural demographics. The mCARE-TBI indicated that most participants (70% and 73% respectively) perceived overall quality of care in the acute and transitional phases was good or very good. Conversely, only 48% perceived chronic care as good or very good. Similarly, healthcare providers (OT, PT, SLP, nurses, physicians) were mostly rated good to very good in acute care (75%), compared with about 50% or slightly higher in rehab. The greatest concerns during the rehab phase was a lack of clarity regarding discharge planning. Specific provider interactional skills were implicated in the greatest concerns across providers. These included listening skills, demonstration of care and compassion, having a positive approach and attitude, acknowledging and validating consequences of TBI, providing information and treating symptoms, and collaborating on treatment planning and goal setting. Qualitative analyses of open-ended survey responses revealed three main positive perceptions and three main negative concerns across phases of recovery. Positive perceptions included *interactional skills of providers, specific supports provided, and effective collaboration*. Negative concerns included *problematic interactions, failure to provide specific supports, and limitations to services*.

Phenomenological findings from the qualitative interviews provide insights into the experience of living with a mild TBI. Along with case reports, core themes across
participants included a *frustrating and exasperating experience*, concerns with *referrals, availability, and following up with providers*, *limited information received about brain injury and what to expect*, and specifics regarding *recovery continuum*. Detailed storylines emerged from phenomenological analyses that provide key insights into refining care processes.

**Conclusions:** Individuals with TBI identify both positive and negative perceptions of their healthcare experiences, which may help healthcare providers to better meet the needs of individuals with TBI in the future. The interactional skills of providers were identified as crucial to effective care. Training specific communication and interactional skills to providers is an important step towards better service delivery. Specific knowledge of TBI and specialized services are critical for supporting individuals with TBI. In the present investigation, those participants who had more access to specialized care reported more positive perceptions of healthcare provision across all phases of the recovery continuum. More specialized knowledge may also decrease incidence of dismissing symptoms or discounting an individual with TBI’s thoughts on treatment. Promoting service access through referrals, clear discharge planning and communication, information about resources and services such as community programs and support groups, and coordinated care were all identified as important steps by individuals with TBI. All providers may improve in explaining things clearly upon discharge, involving family in care, and collaborating with the patient in the treatment plan.

Thesis Advisor                  Date
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Table of Contents

Table 1. Age, time post-onset, and gender................................................................. 49
Table 2. How did you hear about the survey? ......................................................... 50
Table 3. Injury severity related demographics............................................................. 54
Table 4. Points of care. .............................................................................................. 54
Table 5. Follow-up care times. .................................................................................. 55
Table 6. Therapy services. ......................................................................................... 55
Table 7.1 Acute care positives. ................................................................................. 70
Table 7.2. Acute care negatives. ................................................................................. 71
Table 8.1. Transitional care positives ............................................................ 73
Table 8.2. Transitional care negatives. ............................................................ 74
Table 9.1. Chronic care positives .............................................................................. 76
Table 9.2. Chronic care negatives .............................................................................. 77
Table 10. Age, time post-onset, gender, ethnicity, and race. ....................................... 79
Table 11. Injury severity related demographics.......................................................... 80
Table 12. SPRS-2 participant mean scores. ................................................................. 82
Figure 1. Physical, cognitive, psychosocial and economic consequences................. 4
Figure 2. Factors impacting perceptions. ................................................................. 24
Figure 3. Region Identification for the United States. .............................................. 49
Figure 4. Race distribution......................................................................................... 50
Figure 5. Insurance type at time of injury................................................................. 51
Figure 6. Etiology of traumatic brain injury. ............................................................... 52
Figure 7. Pre- and post-injury employment status. ..................................................... 56
Figure 8.1. Overall how were healthcare providers at delivering quality care in the
following settings? ................................................................................................. 57
Figure 8.2. Percent of ratings per provider type for meeting acute care needs (mCARE-TBI question 2)................................................................. 58

Figure 8.3. Percent distribution of ratings per provider type for assisting with transition home (mCARE-TBI question 3)................................................................. 59

Figure 8.4. Percent distribution of ratings per provider type for explaining things clearly upon discharge (mCARE-TBI question 4)................................................................. 60

Figure 8.5. Percent distribution of ratings per provider type for involving family members in care upon discharge (mCARE-TBI question 5)................................................................. 61

Figure 8.6. Percent distribution of ratings per provider type for really listening (mCARE-TBI question 6)................................................................. 62

Figure 8.7. Percent distribution of ratings per provider type for showing care and compassion (mCARE-TBI question 7)................................................................. 63

Figure 8.8. Percent distribution of ratings per provider type for being positive (mCARE-TBI question 8)................................................................. 64

Figure 8.9. Percent distribution of ratings per provider type for acknowledging the consequences (mCARE-TBI question 9)................................................................. 65

Figure 8.10. Percent distribution of ratings per provider type for treating symptoms and concerns (mCARE-TBI question 10)................................................................. 66

Figure 8.11. Percent distribution of ratings per provider type for collaborating with you (mCARE-TBI question 11)................................................................. 67

CHAPTER 1: LITERATURE REVIEW

I. Long-term consequences of TBI .................................................................................. 1
   Physical consequences: .................................................................................. 4
   Cognitive consequences: .................................................................................. 5
   Psychosocial consequences ................................................................................ 7
   Economic consequences ..................................................................................... 12
   Long-term consequences and change over time: ................................................. 15

II. Implications for lack of clear diagnosis, supports, and education ....................... 16

III. Perceptions of support and acknowledgement of TBI effects ................................ 19
   Perceptions of healthcare providers and the healthcare system ...................... 19
   Perceptions of social support for individuals with TBI and family members .... 22

IV. Therapeutic alliance and effects of perceptions on treatment outcomes .............. 24

V. Perceptions of Case Management ........................................................................ 26

VI. Current Study ........................................................................................................ 28

CHAPTER 2: METHODS ................................................................................................. 31

Part One: Traumatic Brain Injury Perceptions Survey .............................................. 31
   Construction of Survey Questionnaire .................................................................. 31
<table>
<thead>
<tr>
<th>Table Heading</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Recruitment</td>
<td>34</td>
</tr>
<tr>
<td>Participants</td>
<td>35</td>
</tr>
<tr>
<td>Procedures</td>
<td>37</td>
</tr>
<tr>
<td>Analyses</td>
<td>37</td>
</tr>
<tr>
<td>Part Two: Traumatic Brain Injury Perceptions Interview and Questionnaire</td>
<td>39</td>
</tr>
<tr>
<td>Participants</td>
<td>39</td>
</tr>
<tr>
<td>Procedures</td>
<td>41</td>
</tr>
<tr>
<td>Transcripts</td>
<td>43</td>
</tr>
<tr>
<td>Analyses</td>
<td>43</td>
</tr>
<tr>
<td>Part Two: Semi-Structured Interviews</td>
<td>79</td>
</tr>
<tr>
<td>Participants</td>
<td>79</td>
</tr>
<tr>
<td>Quantitative Findings</td>
<td>81</td>
</tr>
<tr>
<td>Qualitative Findings</td>
<td>82</td>
</tr>
<tr>
<td>Case descriptions</td>
<td>84</td>
</tr>
<tr>
<td>Common Themes</td>
<td>91</td>
</tr>
<tr>
<td>Part One: Survey</td>
<td>48</td>
</tr>
<tr>
<td>Quantitative Findings</td>
<td>56</td>
</tr>
<tr>
<td>Qualitative Findings</td>
<td>68</td>
</tr>
<tr>
<td>Part Two: Semi-Structured Interviews</td>
<td>79</td>
</tr>
<tr>
<td>Participants</td>
<td>79</td>
</tr>
<tr>
<td>Qualitative Findings</td>
<td>81</td>
</tr>
<tr>
<td>Qualitative Findings</td>
<td>82</td>
</tr>
<tr>
<td>Case descriptions</td>
<td>84</td>
</tr>
<tr>
<td>Common Themes</td>
<td>91</td>
</tr>
<tr>
<td>CHAPTER 3: RESULTS</td>
<td></td>
</tr>
<tr>
<td>Part One: Survey</td>
<td>48</td>
</tr>
<tr>
<td>Quantitative Findings</td>
<td>56</td>
</tr>
<tr>
<td>Qualitative Findings</td>
<td>68</td>
</tr>
<tr>
<td>Part Two: Semi-Structured Interviews</td>
<td>79</td>
</tr>
<tr>
<td>Participants</td>
<td>79</td>
</tr>
<tr>
<td>Quantitative Findings</td>
<td>81</td>
</tr>
<tr>
<td>Qualitative Findings</td>
<td>82</td>
</tr>
<tr>
<td>Case descriptions</td>
<td>84</td>
</tr>
<tr>
<td>Common Themes</td>
<td>91</td>
</tr>
<tr>
<td>CHAPTER 4: DISCUSSION</td>
<td></td>
</tr>
<tr>
<td>Part One: Survey</td>
<td>108</td>
</tr>
<tr>
<td>Modified CARE-TBI questionnaire across recovery continuum</td>
<td>108</td>
</tr>
<tr>
<td>Qualitative survey findings</td>
<td>117</td>
</tr>
<tr>
<td>Part Two: Semi-structured Interviews</td>
<td>119</td>
</tr>
<tr>
<td>Disruptions to psychosocial reintegration following TBI</td>
<td>119</td>
</tr>
<tr>
<td>The Phenomenon of living with a mild TBI</td>
<td>120</td>
</tr>
<tr>
<td>Clinical Implications</td>
<td>127</td>
</tr>
<tr>
<td>Limitations</td>
<td>129</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>131</td>
</tr>
<tr>
<td>APPENDICES</td>
<td></td>
</tr>
<tr>
<td>Appendix A: CARE measure (Mercer, Maxwell, Heaney, &amp; Watt, 2004)</td>
<td>142</td>
</tr>
<tr>
<td>Appendix B: TBI Perceptions Survey and Modified CARE Questionnaire for TBI</td>
<td>143</td>
</tr>
<tr>
<td>Appendix C: Email Correspondence; Survey Cover and Consent Letter</td>
<td>168</td>
</tr>
<tr>
<td>Appendix D: Interview Consent and Cover Letter Interview Consent</td>
<td>172</td>
</tr>
<tr>
<td>Appendix E: Sydney Psychosocial Reintegration Scale-2 (SPRS-2)</td>
<td>175</td>
</tr>
</tbody>
</table>
CHAPTER 1

LITERATURE REVIEW

Perceptions of post-TBI healthcare experiences by individuals with traumatic brain injury

Patient-reported outcomes are becoming an important contributor to healthcare service evaluation and continuous improvement of services. Therefore, examining perceptions of persons with traumatic brain injuries (TBI) regarding their perceptions of healthcare service delivery is important. To understand the context for their perceptions in the chronic phases of recovery, we must establish the chronic consequences of TBI on physical, cognitive, psychosocial, and economic factors. This is followed by a discussion of healthcare perceptions by individuals with TBI in acute and transitional care, establishing a gap regarding healthcare perceptions in chronic phase recovery.

Perceptions of care are believed to influence therapeutic alliance, a key predictor of recovery. Through this discussion, the importance of examining healthcare perceptions will also be outlined as these perceptions may impact treatment efficacy and outcomes. The following narrative will establish the need to examine perceptions across recovery phases, and especially in the chronic phases of recovery.

I. Long-term consequences of TBI

TBI often results in long-term consequences to physical, cognitive, psychosocial, and economic functions. While severity impacts the degree of consequences, effects can be present across the severity continuum. TBI may negatively impact family relationships, lead to a loss of income, cause social isolation, and result in additional expenses (Corrigan & Hammond, 2013; Khan, Baguley, & Cameron, 2003). Adding to
the complexity of TBI, is not only the presence of these consequences, but the interdependency. TBI has the potential to impact a wide variety of areas and one consequence may lead to additional consequences. For example, an individual may experience a physical consequence such as a headache and this may in turn impact psychosocial aspects including mood and behavior; or cognitive aspects like attention and problem solving. Furthermore, as the result of psychosocial symptoms associated with TBI, many individuals may lose their job, which in turn, may lead to increased economic hardship (Gouick & Gentleman, 2004).

According to the Centers for Disease Control and Prevention (2015), approximately 2.5 million emergency department visits, hospitalizations, and deaths in the United States occur from TBI per year. Of the 2.5 million, 87% were treated and released from the emergency department, 11% were hospitalized prior to discharge, and approximately 2% died. However, these numbers are likely an underestimate because many individuals may not receive medical attention, may seek outpatient or office-based visits for injuries or receive care from a federal facility instead. Further highlighting the long-term consequences associated with TBI, it is estimated that between 3.2 and 5.3 million people in the United States live with a disability related to TBI. In other words, 1 in 10 of the 54 million people with disabilities have a disability related to TBI (Langlois, Rutland-Brown, & Wald, 2006). Again, this may be a gross underestimate of prevalence as TBI is a chronic impairment for many of the 2.5 million per year. Estimations for global incidence of TBI suggest that 69 million individuals sustain a TBI each year. Of the 69 million TBIs sustained each year, approximately 81% are classified as mild, 11% as moderate, and 8% as severe (Dewan et al., 2018). Incidence for TBI was greatest in
North America and was estimated to be 1,299 cases per 100,000 people. However, this is again believed to be an underestimate due to the number of mild TBIs that are never reported or seek medical attention (Dewan et al., 2018). The Center for Disease Control and Prevention (2015), also reports individuals with TBI are more than twice as likely to die 3.5 years following injury compared to the general population. Five years post-onset, 2 in 10 individuals with TBI will have died and 4 in 10 will have reduced function from prior levels of recovery (Center for Disease Control and Prevention, 2015). Individuals with TBI experience many long-term consequences and may continue to experience challenges in returning to previous life activities (Langlois et al., 2006). Figure 1 provides a framework for the interaction between the physical, cognitive, psychosocial, and economic consequences of TBI. The following narrative will more explicitly outline the long-term consequences associated with TBI. Through identification of these long-term consequences, the need to consider management and perceptions of healthcare in the chronic phase of recovery is also outlined.
Physical consequences: Physical consequences may include headaches, visual deficits, impaired olfaction, and impaired tandem gait (Ponsford et al., 2014; Vanderploeg, Curtiss, Luis, & Salazar, 2007; Walker & Pickett, 2007). While mobility outcomes are typically good for approximately 75% of individuals with TBI, some individuals may continue to face some more subtle issues related to mobility (Ponsford et al., 2014; Walker & Pickett, 2007). In a study conducted by Walker and Pickett (2007), approximately one third of individuals with TBI showed at least one neuromotor abnormality upon a neurological examination 2 years after discharge from rehabilitation and approximately one fourth of the individuals demonstrated an abnormal tandem gait. Additionally, individuals with TBI may
experience vestibular dysfunction, postural instability, fine motor deficits, and difficulty participating in high-level physical activities (Walker & Picket, 2007).

Fatigue and balance problems are some of the most common symptoms for individuals with TBI and were still present in individuals with TBI 10 years post-onset (Ponsford et al., 2014). Approximately 55% of individuals reported balance difficulties and more than 70% of individuals reported fatigue in the chronic phase of recovery (Ponsford et al., 2014). Other persisting physical consequences identified by approximately one third of individuals with TBI include dizziness, headaches, visual disturbance, and a reduced sense of smell (Olver, Ponsford, & Curran, 1996; Ponsford et al., 2014).

Even individuals with mild TBIs may experience long-term physical consequences including those related to post-concussion syndrome (Vanderploeg et al., 2007). Post-concussion syndrome may include balance problems, frequent headaches, difficulty sleeping, double vision, fatigue, periods of confusion, memory problems, concentration problems, irritability, depression, aggressive behavior, and anxiety (Vanderploeg et al. 2007).

**Cognitive consequences:**

Individuals with TBI may experience ongoing, cognitive impairments including executive function impairments, attention deficits, and reduced processing speeds years after onset (Draper & Ponsford, 2008; Mathias & Wheaton, 2007; Mazaux et al., 1997; Ponsford, Draper, & Schönberger, 2008). According to Draper and Ponsford (2008), individuals with TBI showed impaired attention, processing speed, and executive function 10 years post-onset. These results indicate not only do individuals with TBI
experience cognitive consequences, but for many, these consequences are long-term and still evident a decade after sustaining a TBI. Cognitive status is correlated with functional outcomes and slow processing speed is strongly associated with poorer outcomes including increased difficulty with attention (Mathias & Wheaton, 2007; Ponsford et al., 2008).

As identified by Mathias and Wheaton (2007), individuals with TBI may also experience difficulty with information processing speed and attention deficits. With ongoing cognitive and behavioral changes resulting from TBI, attending school or maintaining a job may be more difficult (Khan et al., 2003; Ruet et al., 2018; Stambrook, Moore, Peters, Deviaene, & Hawryluk, 1990).

Memory impairments are another long-term cognitive consequence associated with TBI and may negatively impact functional communication abilities (Draper & Ponsford, 2008; Murray, Ramage, & Hopper, 2001; Olver et al., 1996; Ponsford et al., 2014; Shum, Harris, O’Gorman; 2000; Vakil, Biederman, Liran, Groswasser, & Aberbucb, 1994). Individuals with TBI may especially have difficulty with word recall, explicit memory tasks, long-term memory, working memory, and with intentional retrieval of information (Murray et al., 2001; Shum et al., 2000; Vakil et al., 1994). This means that it may be more difficult for individuals to remember and learn new information (Murray et al., 2001; Shum et al., 2000). Prior research indicates memory difficulty frequently lasts throughout the chronic phase of recovery (Olver et al., 1996; Ponsford et al., 2014). Olver et al. (1996) found approximately 71% of individuals with TBI reported difficulty with memory 5 years after injury and Ponsford et al. (2014) found
approximately 60% of individuals with TBI reported memory difficulty still present a decade after injury.

Due to cognitive consequences of TBI, individuals may also experience increased difficulty with inhibition and other higher order executive functions, resulting in egocentric communication patterns (Draper & Ponsford, 2008; McDonald et al., 2014; Murray et al., 2001; Ponsford et al., 2014). This has the potential to negatively impact interactions with others. Furthermore, between 25% to 45% of individuals with TBI reported difficulty with planning, initiative, self-centeredness, and impulsivity (Ponsford et al., 2014). Some individuals may also demonstrate difficulty recognizing these problematic communication patterns due to cognitive impairments in self-awareness and this may further impact the rehabilitation process in areas such as employment (Douglas, Bracy, & Snow, 2016).

Even individuals with mild TBIs may experience ongoing cognitive consequences. Cognitive deficits experienced by individuals with mild TBI may include reduced information processing speed and working memory, even on relatively low cognitively demanding tasks (Dean & Sterr, 2013).

**Psychosocial consequences:**

Survivors of TBI experience chronic impairments to cognition, behavior, and social-emotional skills resulting in poor psychosocial outcomes (Ponsford et al., 2008; Ponsford et al., 2014). Psychosocial consequences include emotional, psychological, behavioral, and social consequences. These consequences are interdependent and thus while information related to each of these variables will be provided, it is necessary to
recognize these variables constitute a broader category of psychosocial consequences and are not completely independent from one another.

**Emotional and psychological:** Many individuals experience emotional and psychological effects. Emotional and psychological effects including depression, anxiety, post-traumatic stress symptoms, apathy, and anger are not uncommon for individuals following injury (Bombardier et al., 2010; Gouick & Gentleman, 2004; Jorge et al., 2004). It is estimated that approximately half of people with TBI will have symptoms of depression at some point during the first year following TBI or may develop depression years after injury (Bombardier et al., 2010; Gouick & Gentleman, 2004). There is no difference in rate of major depressive disorder (MDD) between severity levels of TBI and individuals experiencing MDD may also be more likely to report anxiety disorders (Bombardier et al. 2010; Jorge et al., 2004). Depression has been correlated with poorer social functioning for individuals with TBI and may negatively impact recovery (Jorge et al., 2010).

**Social:** Research investigating social effects of TBI indicate ongoing difficulty in maintaining social relationships and feelings of social isolation (Gouick & Gentleman, 2004; Lefebvre, Cloutier, & Josée Levert, 2008). According to Lefebvre et al. (2008), ten years after injury, many individuals reported still feeling “left out”, “isolated” or “cut off from family and friends.” Other than relationships with their partner, an immediate family member, or a close friend, many individuals experienced social isolation. In addition to losing pre-injury relationships, many also experienced a reduction in social
and leisure activities (Gouick & Gentleman, 2004; Olver et al., 1996; Ponsford et al., 2014). In a study conducted by Ponsford et al. (2014), only half of individuals returned to previous leisure activities and approximately 30% reported difficulties in personal relationships a decade after onset. This is especially critical as research has indicated more social activity is correlated with better emotional well-being and lower levels of depression (Brown, Gordon, & Spielman, 2003). Steadman-Pare, Colantonio, Ratcliff, Chase, and Vernich (2001), further identified social support including getting along with others, availability of emotional support, and availability of others to help, as strongly correlated with quality of life. Additionally, psychosocial variables including community integration, life satisfaction, and social support may impact symptoms of TBI (Stålnacke, 2007). This suggests long-term social effects of TBI are important to consider as they may further impede or support recovery for individuals with TBI.

Even individuals with mild TBIs may experience long-term consequences impacting social life. Konrad et al. (2011) found that individuals who sustained a mild TBI over five years prior, continued to experience long-term cognitive and emotional effects impacting everyday social and professional life. When compared to individuals who have not had a TBI, individuals with mild TBIs have poorer psychosocial and quality of life outcomes. In addition, individuals with mild TBIs are more likely to report less satisfaction with social system and overall less social support available (Finset, Dyrnes, Krogstad, & Berstad, 1995).

Previous research has indicated individuals with TBI may demonstrate difficulty with pragmatic aspects of language including emotion recognition, theory of mind, and cognitive flexibility (McDonald et al., 2014; Milders, Ietswaart, Crawford, & Currie,
The difficulties experienced in pragmatic language may lead to increased difficulties following conversations and displaying appropriate social behaviors (Ponsford et al., 2014). These deficits in executive function may also make it more difficult for individuals with TBI to independently contribute to social communication interactions (McDonald et al., 2014). The negative impact of social communication interactions may then negatively impact personal relationships and social-emotional outcomes.

Not only does TBI result in long-term consequences for the individual, but there is also evidence indicating there are long–term consequences for the family as a whole (Gouick & Gentleman, 2004; Khan et al., 2003; Kneafsey & Gawthorpe, 2004; Lefebvre et al., 2008; Schönberger, Ponsford, Olver & Ponsford, 2010). Kneafsey and Gawthorpe (2004) suggest the range of physical, emotional, cognitive, social, and behavioral consequences occurring following TBI may impact both the individual and their families’ everyday lives. The family members of individuals with TBI may be more likely to experience stress and anxiety due to their new role as a caregiver and the behavioral and mood changes of the individual with TBI (Kneafsey & Gawthorpe, 2004; Schönberger et al., 2010). Schönberger et al. (2010) indicated approximately one-third of relatives reported an unhealthy level of family functioning as long as 5 years post-injury and identified a reciprocal relationship between family functioning and relatives’ mood. Therefore, the changes occurring in the individual as a result of the TBI may impact the family as a whole and the well-being of family members.

According to Lefebvre et al. (2008), approximately one third of family members or caregivers reported the individual’s TBI affected their professional life or occupation,
making it difficult to balance work and caring for the individual with TBI. These findings indicate not only may the individual with TBI experience difficulty in working and financial stress, but the entire family unit may also experience this (Lefebvre et al., 2008; Stambrook et al., 1990). Additional long-term consequences for family members included physical and emotional exhaustion (Lefebvre et al., 2008). Given that the family unit is often one of the primary social connections for the individual with TBI, it is critical to consider the impact of TBI on the family dynamic as well when considering long-term consequences (Lefebvre et al, 2008). It may be necessary to provide support for the individual with TBI and families after acute and post-acute rehabilitation.

**Behavioral:** Furthermore, individuals with TBI may experience behavioral changes including increased irritability, anger, and apathy (Gouick & Gentleman, 2004; Vanderploeg et al. 2007). Ponsford et al. (2014) found that approximately 60% of individuals with TBI reported changes in behavioral function at two, five, and ten years post-onset. Furthermore, approximately 2/3rd of individuals with TBI identified irritability as a problem (Ponsford et al., 2014).

Individuals with TBI may also display aggressive behaviors (Baguley, Cooper, & Felmingham, 2006). In a study conducted by Baguley et al. (2006), at 6, 24, and 60 months post-onset, approximately 25% of the participants displayed aggressive behaviors at each time period. While aggression may vary from individual to individual, the current data indicates the overall prevalence of aggression is consistent across time and identifies aggression as a long-term consequence for some individuals with TBI. Other psychosocial variables such as mental health, depression, and satisfaction with life were
predictive of aggression further indicating the interdependency of psychosocial factors (Baguley et al., 2006).

These behavioral and mood changes experienced by individuals with TBI negatively impact family functioning as a whole (Schönberger et al., 2010). This impact on the family is especially critical to consider, given research on social consequences of TBI. Aggression was identified as one of the hardest changes to adjust to following TBI and may increase stress for family and caregivers (Baguley et al., 2006). The more severe the behavior problems exhibited by the individual with TBI, the greater emotional distress reported by relatives (Baguley et al., 2006; Milders et al., 2008). Again, given the large impact that changes in behavior may have on both the individual and family members, additional family support for individuals with TBI and caregivers for at least five years post-onset may be necessary (Baguley et al., 2006).

**Economic consequences:**

As a result of these long-term consequences, many individuals may experience difficulty returning to work. In fact, TBI is the leading cause of disability and job loss for young adults (Ruet et al., 2018). Vanderploeg et al. (2007) suggested underemployment for individuals with mild TBI may be associated with post-concussion symptoms, depression, and problems with attention. Individuals with TBI may also have difficulty returning to work because of cognitive and physical limitations secondary to injury (Stambrook et al., 1990).

For many individuals, returning to work after sustaining a TBI may require obtaining a job with lower status or with fewer demands than their pre-injury job (Stambrook et al., 1990; van Velzen, van Bennekom, Edelaar, Sluiter, & Frings-Dresen,
In fact, approximately 80% of individuals with moderate TBI returning to work, experienced a decrease in socioeconomic job status (Stambrook et al., 1990). Of individuals with severe TBI, only approximately 55% were employed full-time post-injury (Stambrook et al., 1990). Even for those that do return to work, maintaining a job and job stability over time may be difficult for individuals with TBI. In a study conducted by Olver et al. (1996), approximately 32% of the individuals working two years after injury were not working five years after injury.

With the increased medical costs accrued during injury and following injury, inability to work or changes in work may lead to an increase in economic stress associated with TBI (Stambrook et al., 1990). According to Stambrook et al. (1990), vocational status may also impact marital relationships and may be a major stressor for the family following injury. It is estimated approximately two-thirds of individuals with TBI lose their job as a result of TBI and psychosocial symptoms associated with the injury (Gouick & Gentleman, 2004). Only approximately 40% of individuals with TBI are employed within the first 4 years post-onset (Ruet et al., 2018; van Velzen et al., 2009). Ponsford et al. (2014) evaluated outcomes for individuals with TBI at two, five, and ten years post-onset and found that at each follow-up, less than half of individuals were employed. This suggests that difficulty with employment for some individuals with TBI may last upwards to ten years or more post-onset. Ongoing cognitive difficulty may result in difficulty with executive function leading to a loss of social autonomy and further making work following injury difficult (Mazaux et al., 1997).

Employment is associated with quality of life following TBI (Ruet et al., 2018; Steadman-Pare et al., 2001; van Velzen et al., 2009). Employment is linked to increased
participation, provides opportunities for social integration, promotes well-being and health status, and a better quality of life (Steadman-Pare et al., 2001; van Velzen et al. 2009). According to Ruet et al. (2018), more than half of individuals with TBI indicated returning to work improved quality of life (QOL) either “enormously” or a “a lot.” Similarly, individuals with TBI that were employed, indicated higher QOL than those that were unemployed (Steadman-Pare et al., 2001). This indicates that not only is employment after TBI important for economic reasons, but also for overall quality of life.

Job instability for individuals with TBI is not only a problem for the individual, but for society as a whole. Most of the societal costs associated with TBI occur due to long-term underemployment and the lower rates of stability in employment for individuals with TBI (Meulenbroek & Turkstra, 2016). Feinstein and Rapoport (2000), evaluated the cost of TBI in Canada and estimated direct costs associated for mild TBI are $125 million per year and indirect costs are triple this amount, approximately $441.7 million. Furthermore, it was estimated that by 2019, the economic costs associated with accidental injuries such as TBI would be $3.3 billion (Feinstein & Rapoport, 2000). Humphreys, Wood, Phillips, and Macey (2013) indicated similar costs are associated with head injuries in the United States. It was estimated cost of all head injuries in the United States as of 1991 were nearly $200 million and predicted to rise. In 2010, in-hospital costs alone were estimated as $21.4 billion (Marin, Weaver, & Mannix, 2017). Furthermore, it is estimated costs per case of TBI in the UK are between $33,284 and $35,954 for mild TBI and between $25,174 to $81,153 for moderate TBI (Humphreys et al., 2013). While there is some variability in cost from country to country, the overall costs associated with TBI are high.
**Long-term consequences and change over time:**

There is some evidence that not only are long-term effects of TBI present, but that effects may be dynamic and change years after onset. Following injury, it is common for cognitive deficits, depression, psychosis, and social isolation to be ongoing or reemerge following injury. Some evidence indicates there is an association between moderate and severe TBI and progressive neurodegenerative diseases such as Alzheimer’s and Parkinson’s (Corrigan & Hammond, 2013; Li et al., 2017; Nordström & Nordström, 2018). The risk of a diagnosis for dementia increased by 80% for individuals with TBI fifteen years post-onset (Nordström & Nordström, 2018). Additionally, individuals with TBI are four to six times more likely to receive a diagnosis of dementia within a year after sustaining a TBI. The risk for dementia following TBI is stronger for individuals with severe TBI and with multiple TBIs (Nordström & Nordström, 2018). Due to the associated long-term consequences and potential for development of progressive neurodegenerative diseases identified in the literature, TBI may more appropriately be treated as a chronic health condition (Corrigan & Hammond, 2013; Li et al., 2017; Nordström & Nordström, 2018; Rutherford & Corrigan, 2009).

The long-term effects associated with TBI are complex. This indicates individuals with TBI may benefit from ongoing support to address the complex issues related to physical, cognitive, psychosocial, and economic effects of TBI. Frequently, the true complexity and impact of the TBI may only become apparent when evaluating the long-term consequences (Kneafsey & Gawthorpe, 2004).

Given the magnitude of chronic impairments and consequences of TBI, it is critical to identify how effectively these impairments are currently managed through
evaluation of current perceptions and supports provided to individuals with TBI. Current issues that may impact perceptions and supports identified in the literature will be addressed within section II.

II. Implications for lack of clear diagnosis, supports, and education

Researchers have identified ‘lack of clear diagnosis’ as an issue with the potential to lead to feelings of marginalization and reduced access to adequate healthcare (Duff, Proctor, & Haley, 2002; Sample & Darragh, 1998). One barrier identified in the literature to accessing healthcare is lack of sensitive assessment instruments for individuals with mild TBIs (Duff et al., 2002; Wong, Murdoch, & Whelan, 2010).

A qualitative survey of speech-language pathologists conducted by Duff et al. (2002), indicated there currently are few diagnostic tools sensitive enough to identify the cognitive and communication impairments associated with mild TBI. The survey revealed two of the three most frequently used assessment tools by SLPs for evaluation of TBI were aphasia instruments. Duff et al. (2002) discussed the risk of under identification of individuals with TBI through the use of these assessments. TBI and aphasia are different types of neurological disorders with different impacts on cognitive-communication. This may lead to identification of individuals with mild TBI as normal on these assessments because the difficulties they experience are not the same as those an individual with aphasia may experience.

Wong et al. (2010) also discussed the lack of sensitive tools in the evaluation of individuals with TBI. Using a group comparison design, four individuals with mild TBI were evaluated through various assessment batteries six months post-onset. Results of this study indicated individuals with mild TBI scored below average on assessment tasks
involving higher-level language skills such as inferencing, identifying synonyms and antonyms, and words with multiple definitions. The cognitive deficits associated with mild TBI while present, are not always identified on formal assessments as these difficulties occur with higher-level language. Wong et al. (2010) concluded general language assessment batteries may not be sensitive enough to the subtle cognitive-linguistic deficits that occur with mild TBI. Without adequate assessment, it is unlikely individuals with TBI will receive necessary services.

The qualitative, phenomenological study conducted by Sample and Darragh (1998) indicated lack of a definitive diagnosis or misdiagnosis of TBI may lead to loss of self-esteem, depression, and strained family relationships. Individuals with TBI frequently feel disregarded or overlooked, particularly those with mild to moderate TBI. Sample and Darragh (1998) further identified that individuals with mild TBI feel marginalized by their physicians, stating their problems did not seem important to the physicians. These individuals even reported feeling marginalized by peers with more severe brain injuries, who sometimes infer that their problems were more important or real. Peers without TBI commonly state that they have similar challenges as persons with TBI, minimizing or attempting to normalize their reported challenges. Such frustrations can leave a person with TBI feeling outcast and underserved.

Further complicating the issue of accurate diagnosis relates to detection of changes and doctors’ perceptions of severity. TBI is often referred to as an invisible injury. This means it may not appear anything is wrong to the casual observer after a few weeks or months have passed. However, for the individual with TBI, this is often not the case – their reality is often very different. Results from Gouick and Gentleman (2004)
indicated many doctors may discount or miscalculate the effects of TBI, with some viewing the problems as more transient than they are in reality. As previously identified, many individuals will likely experience long-term consequences associated with their injury. When doctors overlook or ignore ongoing clinical symptoms, then the opportunities to provide additional services and support from experts are also missed (Gouick & Gentleman, 2004). Furthermore, limitations of neuroimaging may result in increased difficulty in objectively validating clinical symptoms reported by individuals with TBI. According to Konrad et al. (2011), the lasting disruption of neurofunctional circuits may not be detected through standard structural MRIs, especially for individuals with mild TBI. Additionally, for individuals still experiencing long-term symptoms, CT scans may not adequately document the full impact of the injury on chronic executive function impairments (Draper & Ponsford, 2008). This may lead to doctors and other medical providers creating an artificial timeline for full recovery. This lack of understanding occurring between medical providers and the individual with TBI may lead to increased feelings of frustration, feeling marginalized, and discounted.

The feelings of misunderstanding, marginalization, and frustration are likely to be experienced in other contexts as well. For individuals with TBI, the individual’s family roles are often the only ones left to allow them to live a social life without feeling marginalized and excluded (Lefebvre et al., 2008). Many individuals identified sustaining and strengthening relationships as an area of difficulty. This difficulty with social relationships following TBI may lead to deterioration of social networks and increased feelings of marginalization, exclusion, and isolation (Lefebvre et al., 2008). Overall, this
may result in decreased social support and community support. Section III will identify perceptions related to available supports more explicitly.

III. Perceptions of support and acknowledgement of TBI effects

Perceptions of healthcare providers and the healthcare system:

Several researchers have investigated perceptions of healthcare providers and the healthcare system (Andelic, Soberg, Bernsten, Sigurdardottir, & Roe, 2014; Dams-O’Connor, Landau, Hoffman, & St. De Lore, 2018; Jourdan, Azouvi, Vittala, Timlin, & Jenovuo, 2017; Heinemann, Sokol, Garvin, & Bode, 2002; O’Callaghan, McAllister, & Wilson, 2010; Piccenna, Lannin, Gruen, Pattuwage, & Bragge, 2016; Manskow et al., 2018; Turner, Fleming, Ownsworth, & Cornwell, 2008). In a qualitative review of the transition of hospital to home or a community setting, Piccenna et al. (2016), identified various themes present within the literature. The qualitative review was conducted of studies that included individuals with acquired brain injury and/or family members and caregivers. Themes presented in this review included poor communication, limited participation, and disorganized arrangements for receiving support services for transitioning from hospital to home or community settings. Additionally, all studies reviewed expressed information regarding care and treatment was insufficient from the perspective of patients and family members. Most studies reviewed reported family and caregivers were not involved in discharge arrangements or decisions about care. In general, patients and family members of people with acquired brain injury did not feel adequately prepared at the time of discharge and during transition to the home setting. Lefebvre et al. (2008) suggested long-term difficulties experienced by family caregivers may have been aggravated by the lack of resources provided for long-term follow-up. A
lack of resources related both to transition from hospital to home and to long-term follow-up may lead to increased frustration, stress, and anxiety levels for family members of individuals with TBI. However, to what extent this impacts the chronic phase of recovery is still currently unknown.

Findings in the study conducted by Piccenna et al. (2016) are consistent with those of the Turner et al. study conducted in 2008. Despite being nearly a decade apart, both Piccenna et al. (2016) and Turner et al. (2008) indicated presence of the same themes for the transition of hospital to home. Turner et al. (2008) also found the transition from hospital to home was frequently described as difficult. There was overall a lack of support and lack of individualized care identified from the perspective of patients and caregivers.

Manskow et. al (2018) further evaluated the experiences within the healthcare system of family members following severe TBI. Using a longitudinal research design, Manskow et al. (2018) assessed family member experiences with care provided during the acute phase and during in-hospital rehabilitation. The study revealed overall satisfaction with care was fairly high. Generally, family members felt satisfied with how they were treated as a stakeholder. Family members of individuals who received non-specialized rehabilitation reported lower satisfaction ratings. Respondents identified having the best experience during the acute phase and the worst experience during the discharge phase. Similar to findings by Piccenna et. al (2016), Manskow et al. (2018), identified challenges following discharge. Family members reported not receiving information about consequences of TBI or the dependency level of the individual with TBI. Gouick and Gentleman (2004) identified not only was the transitional phase a
difficult time, but the increased family burden and distress including increased anxiety and depression was actually greatest during the first year following injury. Therefore, while individuals with TBI and family members may generally be content with treatment received during the acute phase of recovery, current research identifies many family members feel underprepared for the transition home and supporting the individual with TBI following hospital discharge (Manskow et. al, 2018; Gouick & Gentleman, 2004; Piccenna et. al, 2016; Turner et al., 2008).

Similar findings to those by Piccena et al. (2016), Turner et al. (2018), and Manskow et al. (2018), were identified by O’Callaghan et al. (2010). O’Callaghan et al. (2010) examined perceptions of individuals with moderate to severe TBIs in Australia across the recovery continuum. Results from this study indicated individuals generally had good access to acute care, less access to specialized services following discharge, and lack of ongoing services in the chronic phase. Most participants were happy or extremely happy with overall care received. However, barriers to healthcare were also identified, including the limited involvement of participants in their own rehabilitation. While this study provides critical information about healthcare perceptions throughout the recovery process, there is still currently little information known about the perceptions of individuals in North America across phases of recovery. Additionally, this investigation focused primarily on individuals with moderate to severe TBIs, and thus little is known about perceptions across the continuum by individuals with mild TBIs.

There are currently unmet needs for individuals with TBI identified in the literature specific to healthcare perceptions in the chronic phase of recovery (Andelic et al., 2014; Dams-O’Connor et al., 2018; Heinemann et al., 2002; Jourdan et al., 2017).
Common unmet needs of individuals with TBI in healthcare during the chronic phase include lack of information on TBI and continued specific rehabilitation needs for motor, cognitive, emotional, and vocational skills (Andelic et al., 2014; Jourdan et al., 2017). These unmet healthcare needs may have the potential to result in decreased life satisfaction, overall health, and mental state (Heinemann et al., 2002). Improving communication between patients and providers, as well as provider specific knowledge about brain injury, may assist in providing more adequate care for individuals with brain injury (Dams-O’Connor et al., 2018). While research has identified some of these chronic phase perceptions, there is again, minimal information known about healthcare perceptions by individuals with TBI in North America as well as for individuals with mild TBIs and thus more information is necessary.

**Perceptions of social support for individuals with TBI and family members:**

Perceptions of support for individuals with TBI and their family members has also been investigated (Manskow et. al, 2018; Finset et al., 1995; Piccenna et al., 2016). Finset et al. (1995) evaluated self-reported social support two years post-onset of TBI. Several participants (33%) reported feeling that they did not have a close relationship with anyone. More than half of participants (57.4%) reported their social networks declined after injury. Additionally, individuals with a higher initial severity level reported feeling more adequately supported than individuals with less severe injuries.

Lefebvre et al. (2008) assessed satisfaction with social integration following injury and found approximately half of individuals with TBI were ambivalent or dissatisfied with their social integration ten years after injury. Additionally, many participants discussed a shortage of post-rehabilitation resources and needing to look for
their own resources. Findings also indicated satisfaction with social integration may be related to having a social life and the support received from family and caregivers. Social reintegration may be important to consider as well as ways to provide resources for support in this process.

Current research indicates TBI may lead to social isolation. TBI may also result in long-term difficulties with social integration (Lefebvre et al., 2008; Khan, et al., 2003; Brown et al., 2003; Jorge et al., 2004; Humphreys et al., 2013). Furthermore, perceptions of severity by the support network may impact the amount of support provided. More research investigating initial severity level and perceived levels of support may be beneficial. It may be of value to investigate if initial severity level impacts other areas of care in addition to support networks.

This information is especially critical to consider given what is known about the relationship between perceptions of support and outcomes. According to Khan et al. (2003), despite initial severity level of injury and type of rehabilitation, individuals with no support or inadequate support had worse outcomes. Therefore, the support provided is necessary to consider and to evaluate as it relates to improving outcomes for individuals with TBI. Figure 2 summarizes the information discussed in this section and displays some of the factors impacting perceptions for individuals with TBI.
IV. Therapeutic alliance and effects of perceptions on treatment outcomes

Some researchers have investigated therapeutic alliance and perceptions as it relates to effects of treatment outcomes (Darragh, Sample, & Krieger, 2001; Schönberger, Humle, & Teasdale, 2006a; Sherer et al., 2007). In a phenomenological qualitative study conducted by Darragh et al. (2001), individuals with acquired brain injury identified qualities of medical rehabilitation providers that are beneficial or detrimental to the rehabilitation process. This study indicated the practitioner-client relationship had the greatest impact on perception of treatment, even more than technical experience. Findings also indicated individuals involved in the treatment planning process felt more in control of treatment. Overall, personal characteristics of providers, perceived helpfulness of services and the practitioner-client relationship, were critical factors and impacted perceptions of care. Therefore, if the professional-client relationship is poor this may result in perceptions of services as incomplete, ineffective, and possibly detrimental to the recovery process.
Schönberger et al. (2006a) identified an interaction between therapeutic alliance, patients’ compliance, and awareness in the process of brain injury rehabilitation. Findings from this study suggested the client’s experience of the emotional bond with their therapist was predictive of clients’ awareness level. In fact, emotional bond was identified as just as predictive, if not slightly more predictive, than localization of the injury and the brain injury itself for levels of awareness during rehabilitation. Essentially, a good working relationship, specifically as it relates to a good emotional bond is important for rehabilitation outcomes and particularly awareness. In another paper involving the same participants in this study, the experience of a good emotional bond between the client and therapist at mid-therapy was also predictive of a reduction of depressive symptoms (Schönberger, Humle, & Teasdale, 2006b). Overall findings support working alliance is a critical component of successful rehabilitation for brain injury, especially as it relates to awareness and reducing depressive symptoms.

The importance of therapeutic alliance for individuals with brain injuries as it relates to family perceptions has also been evaluated. Sherer et al. (2007) found poorer therapeutic alliance led to higher levels of family discord. Additionally, the discrepancies observed between family and clinician ratings for patient functioning were not only associated with poorer therapeutic alliance, but also poorer effort in therapies. Poor participation and effort was predictive of post-acute brain injury rehabilitation program dropout. Furthermore, discharge productivity status was predicted by evaluation of functional status at admission and the degree of therapeutic alliance. This further identifies the relationship between therapeutic alliance and outcomes of brain injury.
rehabilitation. Therefore, it may be beneficial for providers to address family perceptions and functioning in order to increase therapeutic alliance as well as patient outcomes.

V. Perceptions of Case Management

One aspect that may make case management more complex is again, much of the disability and costs associated with TBI are hidden. This may lead to increased frustrations for the individual with a TBI. There may not be any physical evidence of the ongoing consequences of the injury (Khan et al., 2003). Thus, it is important to consider not only physical evidence, but reported symptoms of the individual with TBI and their perceptions. Perceptions of case management are important to consider in identification of current service-delivery.

Research has investigated perceptions of individuals with TBI specifically as it relates to case management (Darragh et al., 2001; Sample & Darragh, 1998). In a study conducted by Sample and Darragh (1998), all participants identified problems with service providers and service systems. Participants also reported lack of coordination of care among providers as a major issue. Sample and Darragh (1998), concluded implementing a better case management system and educating service providers may improve quality of care for individuals with TBI. This study primarily focused on accessibility of care for women within rural communities. It may be beneficial to evaluate overall healthcare across the continuum and with individuals living in different geographical regions to gain additional insight into these issues. Darragh et al. (2001) provided additional information about key practitioner qualities valued by patients throughout recovery. However, it may be beneficial to investigate additional factors that
may impact overall healthcare perceptions for individuals, especially in the chronic phase of recovery.

In addition to these findings, Lefebvre et al. (2008), also identified perspectives related to aspects of case management. Many participants in this study reported receiving a lack of resources after injury, specifically related to social reintegration. Additionally, many identified separation or divorce following brain injury, occurred in part, because of the lack of information and education provided to caregivers about the long-term consequences of the TBI and necessary role changes. Schönberger et al. (2010) further emphasize the importance of supporting relatives of individuals with TBI to cope with depressed mood changes as a part of case management. While issues related to social reintegration and psychosocial factors have been identified, more information about experience within healthcare may provide additional information about the current process of education and resources provided specifically by medical professionals to support individuals after sustaining a TBI.

It may be necessary and beneficial to consider ways to improve case management given the current information presented in the literature. According to Corrigan and Hammond (2013), changing the way patients are educated and incorporating, periodic therapy to assist with some of the long-term effects associated with TBI may provide benefit to individuals with TBI. While this is identified as a potential way to assist, there is currently a need for additional research identifying current perceptions of long-term management. Identifying the perceptions within the chronic phase of recovery is an additional element necessary for improving long-term supports to address chronic management needs. Through identifying current healthcare perceptions, more specific
and detailed information for improving service-delivery and outcomes for individuals with TBI may be provided.

VI. Current Study

The current literature identifies that many individuals with TBI will experience long-term consequences. The long-term consequences experienced by individuals with TBI are sometimes exacerbated as a result of barriers to healthcare access. Some of these barriers include lack of a clear diagnosis, feeling marginalized, lack of support, poor therapeutic alliance, lack of information, and inadequate case management (Darragh et al., 2001; Gouick & Gentleman, 2004; Jourdan et al., 2017; Khan et al., 2003; Sample & Darragh, 1998; Schönberger et al. 2006a; Schönberger et al., 2006b; Sherer et. al, 2007).

Previous research has identified the importance of both the perceptions of individuals with brain injury and family members to overall care and recovery (Lefebvre et al., 2008; Schönberger et al., 2006a; Schönberger et al., 2006b; Sherer et al., 2007). Lefebvre et al. (2008) concluded allowing clients and caregivers to describe their reality may be one way to improve access and allow for professionals to determine better interventions for people with TBI and their families. Prior research also indicates self-reported measures and personal attitudes may have the potential to impact functional outcomes (Sherer et al., 2014). Therefore, more information related to patient perceptions and the reality individuals with TBI face is necessary.

Additionally, as is identified in the current literature, it is necessary to consider ways of providing long-term support to people with TBI and family caregivers. Previous literature suggests individuals and family caregivers may feel inadequately supported and report a lack of post-rehabilitation resources received, especially following acute care,
but there is currently a lack of information identifying perceptions of support specifically during the chronic phase of recovery (Manskow et al., 2018; Lefebvre et al., 2008; Piccenna et al., 2016). Current research for chronic phase perceptions has primarily been conducted in countries outside of the United States, with a focus on individuals with moderate and severe TBIs (Andelic et al., 2014; Jourdan et al., 2017; O’Callaghan et al., 2010). This research indicates there are many ongoing, unmet healthcare needs for individuals with TBI in the chronic phase of recovery and there is a lack of patient involvement in treatment planning (Andelic et al., 2014; Jourdan et al., 2017; O’Callaghan et al., 2010). Based upon what is known about the United States and the chronic phase of recovery, the unmet healthcare needs may have a negative impact on individuals with TBI, including decreased overall quality of life, health, and mental well-being (Heinemann et al., 2002). Thus, it is necessary to obtain specific information about the chronic phase of recovery for individuals across the United States in order to provide additional information and to potentially reduce the negative effects of unmet needs. More information is also necessary specifically related to individuals with mild TBIs during the chronic phase of recovery. Current information about long-term management also indicates a lack of resources for social reintegration and identifies important provider characteristics that may impact client perceptions (Dams-O’Connor et al., 2018; Darragh et al., 2001; Lefebvre et al., 2008). Additional information may provide a more holistic view of healthcare perceptions from the acute to the chronic phase of recovery.

More information related to patient perceptions of services received is thus necessary. By identifying the relationship between the process of rehabilitation and outcomes from the perspective of the patient, the therapeutic process for individuals with
TBI may be improved (Schönberger et al., 2006a). Therefore, to improve service-delivery and patient-reported outcomes, it is necessary to investigate the perceptions of individuals with TBI, especially as it relates to chronic phase perceptions.

The present investigation aimed to answer the following research question:

What are the perceptions of individuals with traumatic brain injury as it relates to service delivery and healthcare in the acute, transitional, and chronic phases of recovery?
CHAPTER 2

METHODS

This study included two parts: the TBI perceptions survey (part one) and the TBI interview (part two). This study was approved by the Institutional Review Board for the Protection of Human Subjects at the University of Wisconsin-Eau Claire (protocol number SPREITKA151542019).

Part One: Traumatic Brain Injury Perceptions Survey

The purpose of the TBI perceptions survey was to gather information from individuals with TBI as it related to their own perceptions regarding recovery from TBI. This included perceptions of injury, healthcare, follow-up from healthcare providers, support networks over time, and changes across time.

Construction of Survey Questionnaire

The portion of the survey investigating perceptions of healthcare experience following TBI was developed based on the CARE measure (Mercer, Maxwell, Heaney, & Watt, 2004). The CARE measure is a psychometrically validated instrument that has been used to measure perceptions of healthcare experience following a single appointment. Present investigators modified this measure in order to more adequately represent healthcare experiences specific to TBI and for ongoing healthcare experience, rather than for a single experience. For ease of reference, the modified scale is referred to as the modified CARE questionnaire for TBI (mCARE-TBI) from this point forward. The original CARE measure can be found in Appendix A and the mCARE-TBI can be found within the survey in Appendix B.
Recommendations provided by Dillman, Smyth, and Christian (2014), were used to ensure the scale provided an appropriate and accurate means of response. This included providing an equal number of possibilities for positive and negative responses as well as for a neutral response. The mCARE-TBI questionnaire developed by the primary investigators included the following five descriptive categories: very poor, poor, fair, good, and very good. Explicit instructions to provide clarity for the intended responses were also provided. For perceptions regarding each phase of recovery (acute, transitional, and chronic), questions were broken up into different sections and additional instructions were provided for each phase. Additionally, changes to overall length of the scale were made to increase response rate. The scale originally consisted of 20 questions, however, the final scale consisted of only 11 in order to reduce redundancy, length, and time necessary for completion.

Survey development methods recommended by Dillman et al. (2014) were used to ensure appropriate format and wording was utilized. This included full question sentences rather than imperative statements, incorporating visuals, and providing multiple choice options for demographic questions. For participants interested in participating in an interview following the survey, a space for sharing contact information was provided.

Content Validity. Questionnaire validation procedures outlined by Boateng et al. (2018) were used in order to validate the mCARE-TBI questionnaire. After developing the scale items, the survey scale was sent to seventeen experts for evaluation to ensure content validity. The scale was distributed to researchers with expertise in the area of TBI and/or in the area of scale validation. Researchers were asked to review the scale and were
provided space for comments after each question. A total of five experts, of seventeen solicited, reviewed, and provided feedback on the scale. Based on feedback provided, the present investigators removed questions, modified verbiage, and modified the structure. After making substantial changes to the scale, the present investigators redistributed the scale to the same group of experts. This time, broad feedback was requested on general structure, wording, and overall impressions. Modifications were again made based on their feedback.

**Face Validity.** Following this initial evaluation of content validity, the scale was distributed to the target population to improve face validity. Group leaders of community-based programs for adults with neurogenic impairments at the College of Saint Rose in Albany, New York distributed the scale to individuals with acquired brain injuries. Group leaders modified access in whatever manner necessary to ensure comprehension of questions and to elicit feedback about accessibility. After reviewing the scale, the individuals with acquired brain injuries were asked to complete a feedback form about content of questions, structure, wording, and relevance to individuals with acquired brain injuries. Based on feedback provided by individuals with acquired brain injuries, additional modifications were made, including addition of audio recorded readings of the questions, larger font, more page breaks, and additional clarification of wording. These specific modifications helped to ensure the survey would be accessible to the population of interest.
Participant Recruitment

Participants were recruited from community-based TBI groups and online TBI support groups. The target for participants was 100 individuals. Researchers recruited individuals that self-identified as a person with TBI. Publicly accessible state associations for brain injury were utilized to obtain contact information for community-based group leaders. Through this process, a list of 818 brain injury support groups with group leader contact information was developed. Group leaders of TBI groups were contacted through phone or email (depending upon their publicly listed contacts) and informed of this research opportunity. Approximately 350 group leaders were contacted via phone and read a script overviewing the project. Phone calls were conducted by the primary investigator and two speech-language pathology graduate students. The script included a request for the group leader to provide an email address if interested in sharing with group members. The contact information for the primary researcher and primary research mentor were also provided. The email correspondence sent to group leaders contained the consent and cover letter, see Appendix C for sample email correspondence and consent letter. The remaining approximately 450 group leader contacts were sent an email directly and were instructed to respond to the email if interested in sharing the information with group members.

Group administrators for online Facebook support groups that were likely to be composed of members who identify as having a TBI were also contacted. These groups included: TBI Support and Awareness, Traumatic Brain Injury Support, TBI Hope and Inspiration, Traumatic Brain Injury Support Group, TBI Survivor Support/My Friends Who Know, Post Concussion Syndrome Support Group, Traumatic or Acquired Brain.

34
Injury Support Group, Brain Injury Support Group, and Hope After Head Injury. These recruitment methods were used in order to attempt to recruit a large, more representative sample of potential participants. It is acknowledged that there may be a selection bias associated with people in these online contexts and in community-based groups. It would have been difficult to fully avoid selection bias as recruiting people who may not identify as having a TBI or no longer identify as having a brain injury may not be feasible, outside direct chart review. Further, people who identify as having experienced a TBI and/or still identify as having chronic consequences of that injury were the desired population.

For community-based group leaders contacted, a total of 74 group leaders responded to the initial request and agreed to distribute the study information including the consent and cover letters to TBI support group members. A total of eleven online-based Facebook groups were contacted. Of the eleven online group administrators contacted, only one responded to the request and approved the post for the Facebook page. The information for the study was posted to “TBI Hope and Inspiration”, which consisted of 29,000 members. The remaining group administrators either did not respond to the initial request or upon obtaining additional information did not ultimately approve the request.

Participants

The online Qualtrics link was accessed approximately 170 times and 8 paper copies of the survey were received. However, upon further review, only 87 of the surveys were at least 95% complete. Of the 87 surveys completed, 23 of the participants did not meet criteria for inclusion in this study. Therefore, a total of 64 participants’ survey
responses were included in analysis. This included 5 paper copies of the survey that were received either via mail or scanned, completed copies of the survey received via email.

To meet inclusion criteria for the study, individuals had to be at least 18 years old at time of onset, self-report as having a TBI, be at least one year post-onset, history of only one brain injury, no other neurological deficits unrelated to or prior to the TBI (e.g., stroke, dementia, Parkinson’s disease, and other neurological diseases), or diagnosed psychiatric disorders prior to TBI (e.g. schizophrenia, obsessive compulsive disorder). If the psychiatric disorder was related to the TBI or occurring after the TBI, the individual was still eligible for participation in this study. This exception was provided given the correlation between anxiety, depression, post-traumatic stress disorder (PTSD), and TBI as is well documented in the literature (Bombardier et al., 2010; Gouick & Gentleman, 2004; Jorge et al., 2004). Exclusionary factors for the 23 surveys that were removed prior to analysis included etiology of injury, under 18 years of age at time of onset, less than a year post-onset, under guardianship, or completion by a family member rather than the individual with a TBI.

On the survey, most of this information was self-reported in order to retain confidentiality of participants. In order to obtain confirmatory medical records, an address and access to release of information documentation for pertinent medical facilities would be required. This would compromise the confidentiality and anonymity of the online survey format. To increase likeliness the individual truly had experienced a diagnosed brain injury, questions related to specific information including information such as Glasgow Coma Scale (GCS) upon admittance to the hospital and length of loss of consciousness were used. Overall severity classification was then determined based on
self-reported severity level and responses to self-check questions. A consistency measure was calculated between self-reported severity and self-check responses. Self-check responses were also evaluated for the purpose of severity stratification for contacting individuals for follow-up interviews. Potential participants were not excluded based upon severity as self-reported or verified by medical records because the investigation was seeking persons who identify as having the effects of a TBI.

**Procedures**

A link to an online, Qualtrics survey was attached with the information posted about the study in the correspondence with group leaders, community-based groups, and Facebook groups. Participants were given a consent and cover letter by group leaders of community-based groups and by the primary investigator for Facebook groups. The Qualtrics survey included questions related to demographics, perceptions of healthcare, follow-up services, and satisfaction with service-delivery (Mercer et. al, 2004; Spreitzer & Hoepner, 2019). Demographic questions included employment status, injury severity, and services received.

**Analyses**

Data obtained from the Qualtrics survey was analyzed through quantitative and qualitative measures.

**Quantitative analysis** included the use of descriptive statistics. Means, frequency counts, and percentages across distributions were calculated. While not feasible in the scope of this thesis project, further statistical analyses are planned in order to make direct comparisons for mCARE-TBI questionnaire responses (i.e., comparison across
rehabilitation settings and across providers). Friedman test comparisons will be utilized for analysis to allow for comparison within and across categories. This non-parametric statistic will allow for objective analysis to determine if ratings between providers were statistically significant. Pairwise comparisons between rehabilitation settings and between provider types will also be completed prior to disseminating results for publication. Adjustments are necessary to account for the fact that each individual did not always rate each rehabilitation setting (i.e., they may not have had an inpatient rehabilitation experience to rate) or provider (i.e., they may not have had interaction with all provider types to rate).

**Qualitative analysis.** Survey responses were also analyzed through qualitative coding procedures. Qualitative analysis involved the use of open-axial hierarchical coding and multiple cycles of coding (Miles, Huberman, & Saladaña, 2014; Strauss & Corbin, 1990; Strauss & Corbin, 1997). Multiple rounds of coding were conducted to ensure rigor and stability of codes over time. Coding was completed by the primary investigator, a speech-language pathology graduate student, and her research mentor, a speech-language pathology professor, with over 15 years of experience in qualitatively coding data. During the first round, researchers completed close reading of open-ended responses to immerse themselves in the ideas that were expressed in the responses. This allowed for open-coding procedures to be implemented and for free associations between ideas to be made. During the second round of coding, researchers identified categories of information and began relating the categories of information to form patterns. During this round, axial coding procedures were implemented and connections between codes were
made. This round began to yield overarching and subordinate levels of codes. Consensus coding procedures were used to ensure reliability of codes. For consensus coding, primary investigator established the codes and then the primary research mentor coded for a second time to ensure stability in the codes. This also helped to determine consistency of coding across individuals. During the third round of coding, researchers identified more specific elements that were previously represented in broad categories. The coding hierarchy was solidified during this final round, as was consensus coding. This coding procedure has been outlined by Strauss and Corbin (1997) and Miles et al. (2014) as a valid and reliable way to code information.

**Part Two: Traumatic Brain Injury Perceptions Interview and Questionnaire**

The purpose of the TBI perceptions interview and the Sydney Psychosocial Reintegration Scale Version 2 (SPRS-2) (Tate, 2011) was to gain more detailed information about the topics previously explored through the survey. The last question on the survey allowed for individuals to provide contact information if they were interested in participation in an interview and questionnaire.

**Participants**

Interview participants were recruited from the original 64 survey respondents. Therefore, the inclusion criteria for the interview portion of the study was the same as for the survey. The final survey question provided an opportunity for participants to share contact information for a follow-up interview. A total of 40 out of 64 total survey respondents (62.5%) provided contact information for follow-up interviews.
Survey responses of the 40 interested in interviews were reviewed to allow stratification based on severity level. Self-check responses were evaluated, and severity classification was determined to contact individuals with mild, moderate, and severe TBIs. Prior to participation in the interview portion of the study, participants filled out an additional consent form, which can be found in Appendix D.

Self-check responses were evaluated, and severity classification was determined to contact individuals with mild, moderate, and severe TBIs. For the purposes of the current investigation, only the interviews of five individuals with mild TBIs were analyzed. Polkinghorne (1989) recommends a minimum of five individuals who have experienced a phenomenon. Individuals with mild TBIs were selected based on previous research indicating increased feelings of marginalization and less support within the healthcare setting for individuals with mild TBIs (Duff et al., 2002; Sample & Darragh, 1998; Wong et al., 2010). Additionally, there is currently a lack of information about healthcare perceptions by individuals with mild TBI in the chronic phase. Previous research has primarily focused only on those with moderate and severe TBIs (Andelic et al., 2014; O’Callaghan et al., 2010). Mild TBIs are also more commonly occurring, with nearly 81% classified as mild, 11% as moderate, and 8% as severe (Dewan et al., 2018). Therefore, highlighting these perceptions first may have the potential to help increase support for more individuals sustaining TBIs. Additional analyses in the future will evaluate perceptions of individuals with moderate and severe TBIs and allow for stratification across severity levels.
Procedures

Two online speech-language pathology graduate students, trained in interviewing techniques, conducted the interviews. Interviewers were blinded to the hypotheses of the investigation. The primary researcher trained both graduate students on the methods and procedures for conducting the interviews in order to ensure consistency of administration of interviews. This included explicit instruction on administration of scales and interview questions. The graduate students were also provided guidance for utilization of follow-up questions to ensure adequate information was obtained. Constraints were identified to reduce likelihood of introducing their own biases. This was done to provide consistency in interviews and to ensure the desired information was obtained, while using broad interview questions to allow participants to independently formulate responses.

Prior to engaging in the interview, the SPRS-2 was administered to each participant by one of the interviewers. This scale is a quantitative measure that allows for comparison between pre-injury and post-injury life. This measure was specifically selected as a validated patient-reported outcome measure providing valuable information about life participation. Specifically, it provided key information about psychosocial aspects of post-TBI life and provided additional context that may impact perceptions and attitudes towards healthcare. The SPRS-2 allows for individuals to rate amount of change since injury across three domains: Work and Leisure, Relationships, and Living Skills. On this scale, individuals provide a rating between 0 and 4. A rating of 0 indicates extreme change, 1 indicates a lot of change, 2 indicates moderate change, 3 indicates a little change, and 4 indicates no change at all. For reference of the full scale, see Appendix E.
While the SPRS-2 could have been used as an adjunct to the survey, due to the length of the survey, it was determined that adding this measure may result in decreased survey completion. Furthermore, the information obtained through the SPRS-2 was not as relevant for the desired outcomes of the survey, but provided important additional information for analysis of interviews. Finally, completing the SPRS-2 with the interviewer allowed them to address questions as they arose, as opposed to self-completion on a paper version.

After the SPRS-2 was completed, an interview consisting of open-ended questions was used. Interviews were conducted via BlueJeans (BlueJeans 2.x, 2020), a video conferencing application. BlueJeans videos were recorded through a feature in the BlueJeans video conferencing application and stored in a password protected cloud-based repository. The following interview questions were asked to gain additional information about healthcare perceptions:

1. Describe your experience within the medical setting related to traumatic brain injury.

   The following probes were used as follow-up questions if more information was necessary, or if the participant did not understand the initial question:
   
   - To what extent did they acknowledge your traumatic brain injury and the consequences of that brain injury?
   - In the online survey, we asked about particularly good and particularly bad service providers, can you describe any particularly good ones?
     
     Particularly bad ones?

2. Describe the information you remember receiving related to traumatic brain injury for long-term services and supports?

3. What do you wish you would have known following your injury that you now know?
These questions were intentionally broad in order to provide participants the opportunity to share information they believed to be personally relevant and critical. If specific questions were used, this may have guided participants to respond in a specific way, thus skewing results. Through the use of open-ended questions, participants were able to independently formulate responses. Additional follow-up questions were used to obtain the necessary information only when necessary and were guided through providing the same information and protocol to both interviewers.

Transcriptions

Two research assistants were recruited to transcribe the recordings of the interviews. These research assistants were undergraduate communication and science disorders majors and were provided training in transcription procedures prior to completion. In order to ensure research assistants utilized consistent transcription procedures, duplicate transcription was completed on 2 out of the 5 (40%) of the transcripts. Interrater reliability between transcribers was 88.9% across total participant exchanges. This indicated both transcribers were utilizing consistent procedures.

Analyses.

Data obtained from the interview was analyzed both quantitatively and qualitatively.

Quantitative analysis consisted of calculation of mean scores for the SPRS-2. The SPRS-2 provides a total score and evaluates three domains: Work and Leisure, Relationships, and Living Skills. The SPRS-2 scoring procedures allow for the calculation of mean scores. The descriptors associated with these mean scores can be directly related to the
same descriptions utilized on the scale to identify total perceived change. For example, if an individual provided a rating of 1, indicating “a lot” of perceived change on the scale, and then obtained a mean domain score in the range of 1, the same descriptor utilized by the participant, “a lot” of perceived change was indicated. Essentially, this scoring procedure allowed for consistency between participant identified responses and the analyses. Individual mean scores across the three domains and for the total score were calculated for each participant. Mean scores for each domain and the total score were also calculated across participants to identify overall perceived change.

**Qualitative analysis:** Interpretative phenomenological analysis (IPA) was utilized to analyze data obtained through the semi-structured interviews. This procedure as is outlined by (Brocki & Wearden, 2006; Shinebourne, 2011) has been implemented by other researchers, especially in the area of health psychology, to investigate perceptions and experiences of individuals. Other researchers investigating TBI and aphasia also utilized IPA procedures to provide a comprehensive analysis of semi-structured interviews (Brown, Worrall, Davidson, & Howe, 2010; Hooson, Coetzer, Stew, & Moore, 2013). IPA allows for the individual experience and the contextual factors that may impact an individual’s experience to be carefully considered during analysis. For the purposes of the current research study, IPA offers the ability to analyze the experiences of the individual with TBI across time and across the phases of recovery. IPA also allowed for the examination of key aspects and critical contextual factors relevant to the individual healthcare experience that may have been omitted through implementation of other data analysis procedures. Therefore, because the purpose of the current study was to
identify the current perceptions of individuals with TBI, IPA allowed for thorough and accurate examination of each individual’s experience.

A 5-step methodology based on IPA methods described by Brown et al. (2010) and Hooson et al. (2013) was implemented by the primary investigators for comprehensive analysis of semi-structured interviews. The current investigation used a similar method to the one developed by Brown et al. (2010) which was a 4-stage process, but also added an additional fifth step based on Hooson et al. (2013), allowing for the development of common themes. Additional modification to the procedures included the development and use of textural descriptions, rather than only a summary table. These slight modifications allowed for the use of textural descriptions for each individual participant as well as identification of commonalities across participants. These procedures including the selection of this approach for qualitative analyses is also discussed by Creswell (2006). The specific process of data analysis utilized in this study is outlined below:

1. The primary investigator read and re-read each individual transcript. Key statements including sentences and quotes providing insight into how participants experienced a particular phenomenon were highlighted.

2. From the key statements, clusters of meaning were developed. Themes were formed based on the recurrence of main ideas within the individual transcripts.

3. Textural descriptions were constructed based upon the significant statements and themes. The specific, individualized experience within the healthcare setting was provided through narrative exposition. These descriptions allowed for the rich, unique story of each individual participant to be shared.
4. Information about the specific context and situations that influenced the individual’s experience were added to identify the change in perceptions over time and across phases of recovery.

5. Individual case descriptions and transcripts were reviewed again and commonalities across participants were identified.

As is identified in the fifth step of the methodology utilized in this study, while each individual participant had a unique experience within the healthcare setting, there were also commonalities between experiences. Clusters of meaning were derived from review of statements, which were then grouped as themes (Moustakas, 1994). Thus, thematic analysis was completed in order to identify the connections between the experiences within the healthcare setting. The transcripts were reviewed once again and main ideas present across transcripts were identified. Following methods established by Moustakas (1994) and Polkinghorne (1989), “significant statements” were identified. Significant statement quotes and examples were compiled to illustrate shared perceptions and experiences by individuals with TBI.

Statement of researcher bias: It is recognized that the researchers have clinical experience in the area of TBIs. I acknowledge that this may impact how I code, which is why multiple rounds of coding and consensus coding were utilized. Consensus coding was completed with my primary research mentor in order to assist in reduction of personal biases. Additionally, transcripts were reviewed multiple times and at different points in time to ensure rigor and stability in procedures utilized. It is also necessary to acknowledge a level of subjectivity involved in analysis when following principles of
IPA. Therefore, the previous personal experiences the primary investigator and primary research mentor had in working with individuals with TBI have the potential to impact the interpretative process necessary for completion of IPA.
CHAPTER 3

RESULTS

Part One: Survey

Sixty-four completed surveys were included in analysis of survey results. While sixty-four surveys were at least 95% complete, some participants did not provide an answer to every question, which will be reflected in the analysis. Additionally, if an individual responded to only the first question, their response was still included in response to the questions answered. For a majority of the questions, only 64 participants responded and these responses are included in the overall analysis. While 23 additional surveys were at least 95% complete, these surveys were excluded due to inclusion and exclusion criteria. Exclusionary factors included etiology of injury, under 18 years of age at time of onset, less than a year post-onset, under guardianship, or completion by a family member rather than the individual with a TBI. The survey provided specific demographic information about participants and healthcare perceptions as measured through the mCARE-TBI.

Demographic information. As previously stated, a total of sixty-four participants completed at least 95% of the survey. However, not every participant responded to every question and this will be reflected in the demographic information. Personal demographic variables obtained included region, age, time post-onset, gender, ethnicity, race, insurance type, and the highest level of education.
Figure 3 displays the classification of regions in the United States for the purpose of this study. There were 8 (14%) participants from the West, 28 (48%) from the Midwest, 12 (21%) from the South, and 9 (16%) from the Northeast. There was also one participant residing in Canada.

Survey participants were between the ages of 25 years, 7 months-old and 78 years, 11 months-old. Post-onset time was between 1 year and 52 years, 2 months. For a summary of age, time post-onset, and gender please refer to Table 1.

Table 1. Age, time post-onset, and gender.

<table>
<thead>
<tr>
<th>Mean Age (years, months)</th>
<th>Mean Time post onset (years, months)</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>51;8</td>
<td>9;8</td>
<td>31 or 48.4% male</td>
</tr>
<tr>
<td>Min: 25; 7</td>
<td>Min: 1</td>
<td>33 or 51.5% female</td>
</tr>
<tr>
<td>Max: 78; 11</td>
<td>Max: 52; 2</td>
<td></td>
</tr>
</tbody>
</table>
Participants were asked how they heard about the survey in order to evaluate participation recruitment and to consider whether or not there was a difference between perceptions of individuals in online support groups compared to community-based support groups. However, because online support groups and face-to-face groups are not mutually exclusive, this information was not further evaluated for the purposes of the current study. The responses from this question are displayed in Table 2.

Table 2. How did you hear about the survey?

<table>
<thead>
<tr>
<th>Facebook group</th>
<th>From group leader in face-to-face group</th>
<th>Group leader (reported this)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>34</td>
<td>5</td>
</tr>
</tbody>
</table>

Ethnicity. Of the sixty-four participants, 92% identified as not Hispanic, 6% identified as Hispanic, and 2% indicated a preference not to answer.

Race. The majority of participants, 89%, were white/Caucasian. For the distribution across participants for race, please see Figure 4.

Figure 4. Race distribution.
Insurance Type. Information about insurance type at time of injury was obtained as insurance may have the potential to impact access to healthcare, especially during transitional and chronic phases of recovery. For information about participant insurance type at time of injury, please see Figure 5.

Figure 5. Insurance type at time of injury.

Highest level of education. Information about highest level of education was also obtained. Education level may have the potential to impact interactions in the healthcare setting, although that is not the focus of this investigation. For example, an individual with a bachelor’s degree and working as a medical professional, may potentially have different healthcare perceptions than an individual with only a high school degree and no specific healthcare knowledge. Furthermore, educational background may impact interactions through increased knowledge of availability of resources within the
healthcare setting or questions to ask to obtain additional information for services. The distribution for educational level of the participants was 44% with an advanced degree, 34% with a 4-year college degree, 17% with a 2-year college degree, and 5% with a high school diploma, and 0% with less than a high school diploma.

**Injury related Demographic information:** Demographic information about each participant’s TBI and experiences following injury were obtained through the survey. Etiological mechanisms are shown in Figure 6. Motor vehicle accidents were the most common etiology for TBI in this group of participants.

Figure 6. Etiology of traumatic brain injury.

Information about severity of TBI including the Glasgow Coma Scale (GCS) are displayed in Table 3. This information was self-reported by the participants. GCS is a measure commonly used in healthcare to determine severity of TBI. In calculation of
GCS, the individual’s level of consciousness is identified. The GCS includes evaluation of eyes, motor, and verbal responses. Measurements commonly associated with GCS include loss of consciousness (LOC), coma length, and length of post traumatic amnesia (PTA). Eyes and motor movements relate to consciousness and coma length, and verbal response of confusion corresponds with PTA. PTA was reported by 91.9% (n = 57), reported absent by 6.45% (n = 4), and one individual was unsure.

These measures were utilized on the survey to serve as a crosscheck of presence of TBI and to evaluate consistency of reported severity level. Consistency in reporting was defined as at least 2 responses to the self-check questions corresponding with the severity level identified by the participant. This procedure was selected as the primary purpose of the self-check questions was to ensure respondents had truly sustained a TBI and to allow for stratification of the sample for the interview process. Approximately 63% of respondents were consistent in reporting severity level. However, as Table 3 indicates, nearly 71.6% of participants were unsure of the GCS or GCS was not applicable. Additionally, there were inconsistencies in reporting PTA as a higher distribution reported more than 7 days compared to the number of individuals reporting a severe TBI. This could be related to confusion with this term. While a definition was provided, individuals may still have lacked familiarity with the specific term “PTA”, thus altering the results for this question.

Information for length of hospital stay was also identified. The presence or absence of aphasia is included, as it is found to be associated with more severe impairments (Elbourn et al., 2019). Aphasia was reported present by 26.9% (n = 17)
participants, reported as not present by 57.14% (n = 36), and 15.87% (n = 10) were unsure.

Table 3. Injury severity related demographics.

<table>
<thead>
<tr>
<th>Severity:</th>
<th>GCS:</th>
<th>LOC:</th>
<th>Coma duration:</th>
<th>PTA duration:</th>
<th>LOHS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concussion/</td>
<td>14-15:</td>
<td>0-30 minutes:</td>
<td>Less than a day:</td>
<td>Less than 5 minutes:</td>
<td>1 day or less:</td>
</tr>
<tr>
<td>mild TBI:</td>
<td>3.33% (2)</td>
<td>53.2% (33)</td>
<td>3.28% (2)</td>
<td>5.1% (3)</td>
<td>9.84% (6)</td>
</tr>
<tr>
<td>25.8% (16)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate TBI:</td>
<td>9-13:</td>
<td>30 minutes-24 hours:</td>
<td>1-2 weeks:</td>
<td>5-59 minutes:</td>
<td>2-3 days:</td>
</tr>
<tr>
<td>17.7% (11)</td>
<td>6.67% (4)</td>
<td>16.4% (10)</td>
<td>10.2% (6)</td>
<td>4.9% (3)</td>
<td></td>
</tr>
<tr>
<td>Severe TBI:</td>
<td>3-8:</td>
<td>Greater than 26 hours:</td>
<td>More than 3 weeks:</td>
<td>1-24 hours:</td>
<td>4-5 days:</td>
</tr>
<tr>
<td>46.71% (29)</td>
<td>18.3% (11)</td>
<td>41.9% (21)</td>
<td>24.6% (15)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsure:</td>
<td>Unsure or n/a:</td>
<td>More than a year:</td>
<td>1-7 days:</td>
<td>6-7 days:</td>
<td>8 days or more:</td>
</tr>
<tr>
<td>9.7% (6)</td>
<td>71.6% (43)</td>
<td>0%</td>
<td>6.7% (4)</td>
<td>8.2% (5)</td>
<td>54.1% (33)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I was not in a coma:</td>
<td>More than 7 days:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55.7% (34)</td>
<td>76.3% (45)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>I was not hospitalized or N/A:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>19.7% (12)</td>
</tr>
</tbody>
</table>

Notation: LOC = loss of consciousness, LOHS = length of hospital stay

Table 4 displays points of care in which services were received by participants.

Table 4. Points of care.

<table>
<thead>
<tr>
<th>Rehabilitation facility</th>
<th>Acute care hospital</th>
<th>Trauma center</th>
<th>Outpatient hospital</th>
<th>Transitional care facility</th>
<th>Long-term acute care</th>
<th>Other care</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>28 or 23.33%</td>
<td>23 or 19.17%</td>
<td>21 or 17.5%</td>
<td>13 or 10.83%</td>
<td>8 or 6.67%</td>
<td>4 or 3.33%</td>
<td>6 or 5%</td>
<td>16 or 13.33%</td>
</tr>
</tbody>
</table>

*Participants may have stayed at more than one of these settings. (N=120)
Table 5 indicates points of time in which follow-up care was received.

Table 5. Follow-up care times.

<table>
<thead>
<tr>
<th>Initial only, no follow-up</th>
<th>1 week</th>
<th>1 month</th>
<th>6 months</th>
<th>1 year</th>
<th>More than 1 year</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 or 25 or 28 or 23 or 23 or 42 or 0%</td>
<td>2.08%</td>
<td>17.36%</td>
<td>9.4%</td>
<td>15.97%</td>
<td>29.17%</td>
<td></td>
</tr>
</tbody>
</table>

*Participants may have received services at more than one of these points in time

Information about specific service types (e.g. OT, PT, SLP, and other) received was also obtained. This is displayed in Table 6.

Table 6. Therapy services.

<table>
<thead>
<tr>
<th></th>
<th>SLP</th>
<th>OT</th>
<th>PT</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Count)/%</td>
<td>Yes: (37) 63.79%</td>
<td>Yes: (42) 73.68%</td>
<td>Yes: (52) 89.66%</td>
<td>Yes: (37) 64.91%</td>
</tr>
<tr>
<td>frequency</td>
<td>No: (20) 34.48%</td>
<td>No: (13) 22.81%</td>
<td>No: (4) 6.90%</td>
<td>No: (12) 21.05%</td>
</tr>
<tr>
<td>receiving services</td>
<td>Unsure: (1)</td>
<td>Unsure: (2)</td>
<td>Unsure: (2)</td>
<td>Unsure: (8)</td>
</tr>
<tr>
<td></td>
<td>1.72%</td>
<td>3.51%</td>
<td>3.45%</td>
<td>14.04%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mean # of weeks of services</th>
<th>Mean: 42.43</th>
<th>Mean: 30.74</th>
<th>Mean: 38.08</th>
<th>Mean: 61.24</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard dev:</td>
<td>34.49</td>
<td>31.38</td>
<td>32.04</td>
<td>36.79</td>
</tr>
</tbody>
</table>

**Other Services Received:** TBI and Post-traumatic stress disorder (PTSD), General Psychologist; mental health counseling, brain injury support group, learning disability services through a university; Neuro ophthalmology, counseling, driver evaluation; Opportunities for Ohioans with Disabilities; TBI Waiver, Community Integration Counseling Service (CIC), Independent Living Skills Trainer (ILST), PBLS, Home and Community Support Services (HCSS), day program; Neurologist for seizures; cognitive; cognitive therapy; Home Care; Vision therapy; Neuropsychology visits; psychotherapy; counseling with social worker, Doing Eye movement desensitization and processing (EMDR) and talk therapy; Therapy for PTSD; Counseling; Psychological counseling; Brucker biofeedback, Muscle Activation Technique; Neurological; Cognitive; Nevada Community Enrichment Program (NCEP); Vision therapy; Balance therapy; psych counseling for depression/adjustment disorder;
**Employment.** Employment status is frequently altered post-onset of TBI, however, not all who are unemployed following TBI are seeking employment or wish to be employed. There was a significant difference in pre- and post-injury employment status $t(124) = 10.58, p < .05)$. Pre- and post-injury employment status is displayed in Figure 7.

![Pre- and post-injury employment status](chart.png)

**Figure 7.** Pre- and post-injury employment status.

**Quantitative Findings**

Additional information about perceptions of care by setting and provider-type in different domains was obtained through the mCARE-TBI questionnaire (Spreitzer & Hoepner, 2019). Figures 8.1 – 8.11. display the results from the mCARE-TBI questionnaire reported in the Qualtrics online survey. Figure 8.1 shows overall ratings by healthcare setting (i.e., acute, rehab, or long-term care). Most participants indicated overall quality of care in acute, rehab, and long-term settings were good or very good. However, a smaller percentage of participants rated long-term quality of care as good to
very good and a higher percentage rated experience in long-term as fair, poor, or very poor. Compared to the care received in acute and rehab, there is a slight difference between overall ratings. Figures 8.2–8.11 display ratings of provider types by indicating percent reported per categorical rating (i.e., very poor, poor, fair, good, or very good). Percentages are reported instead of frequency counts because not every participant had an experience in each setting or with each provider. Mean ratings per provider type are also listed per question.

Figure 8.1 Overall how were healthcare providers at delivering quality care in the following settings?

![Bar chart showing ratings for acute care, rehab, and long-term care.](chart)

Question 2 from the mCARE-TBI questionnaire asks: How were healthcare providers at meeting your overall needs in the acute care setting? The majority of providers in the acute care setting were rated between good to very good with only a
small portion rated as fair, poor, or very poor. Mean score for occupational therapists was 4.1 (good), for physical therapists was 4.2 (good), and for speech-language pathologists was 4.2 (good). For doctors, mean score was 4 (good) and for nursing it was 4.1 (good). Thus, indicating most providers were pretty good at meeting acute care needs. See Figure 8.2 for perceived effectiveness of healthcare providers across disciplines (i.e., nursing, occupational therapy [OT], physical therapy [PT], speech-language pathology [SLP], doctors, and other) in meeting needs within the acute care setting.

Figure 8.2 Percent of ratings per provider type for meeting acute care needs (mCARE-TBI question 2).

![Figure 8.2 Percent of ratings per provider type for meeting acute care needs (mCARE-TBI question 2).](image)

Figure 8.3 addresses mCARE-TBI question 3: How were healthcare providers at assisting with the transition home following discharge from the hospital after your TBI… (support provided to facilitate the transition, resources and information provided, information for community-based groups provided)? Approximately 70% of OTs, PTs, and SLPs were rated between good and very good. However, mean rating for OTs was
3.9 (fair, just short of a ‘good’ rating). For PTs, mean rating was 4 (good), and for SLPs mean rating was 4 (good). Only 50% of doctors and nurses were rated between good and very good. For doctors, 23.9% were rated as very poor and 11.9% as poor in providing assistance to transition home. Likewise, 23.4% of nurses were rated as very poor and 4.3% as poor in assisting with the transition to home. The overall mean ratings for both doctors and nurses were 3.2 (fair). This suggests therapists were better than doctors and nurses in assisting with the transition home. A statistical comparison will be conducted to determine significance of this difference. Figure 8.3 for distribution of ratings across providers.

Figure 8.3 Percent distribution of ratings per provider type for assisting with transition home (mCARE-TBI question 3).

In response to mCARE-TBI question 4: How were healthcare providers at explaining things clearly upon discharge… (helping you know what to expect when leaving the hospital, providing information about your brain injury, providing
information for who to follow-up with and when)? Slightly more than 60% of ratings for OTs, PTs and SLPs, were between good and very good for explaining things clearly upon discharge. However, for doctors and nurses, only approximately 40-50% of ratings were between good and very good. For doctors, 29.2% of ratings were very poor and 10.8% were poor. For nursing, 24% were very poor and 8% were poor. Doctors and nurses had the lowest overall mean ratings, 3 (fair) and for nursing 3.2 (fair) respectively. Mean rating for OTs was 3.5 (fair), PTs was 3.6 (fair), and SLPs was 3.8 (fair). All providers had lower ratings for explaining things clearly upon discharge. See Figure 8.4 for distribution of ratings across providers.

Figure 8.4. Percent distribution of ratings per provider type for explaining things clearly upon discharge (mCARE-TBI question 4).

<table>
<thead>
<tr>
<th>Provider</th>
<th>Very Poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>21.4</td>
<td>7.1</td>
<td>28.6</td>
<td>42.9</td>
<td></td>
</tr>
<tr>
<td>Nursing</td>
<td>24</td>
<td>8</td>
<td>20</td>
<td>22</td>
<td>26</td>
</tr>
<tr>
<td>SLP</td>
<td>17.8</td>
<td>4.4</td>
<td>8.9</td>
<td>22.2</td>
<td>46.7</td>
</tr>
<tr>
<td>PT</td>
<td>17.4</td>
<td>6.5</td>
<td>15.2</td>
<td>19.6</td>
<td>41.3</td>
</tr>
<tr>
<td>OT</td>
<td>17.3</td>
<td>7.7</td>
<td>13.5</td>
<td>30.8</td>
<td>30.8</td>
</tr>
<tr>
<td>Doctors</td>
<td>29.2</td>
<td>10.8</td>
<td>15.4</td>
<td>21.5</td>
<td>23.1</td>
</tr>
</tbody>
</table>

Mean Rating:
- Other: 3.2
- Nursing: 3.8
- SLP: 3.6
- PT: 3.5
- OT: 3.5
- Doctors: 3

Question 5 from the mCARE-TBI asks, How were healthcare providers at involving your family members/care partners in your care upon discharge… (receiving
information, supporting their ability to assist with care following hospital discharge)?

Across all providers, there were higher percentages of very poor ratings for involving family members in care in response to this question. Between 30-40% of all provider ratings fell between very poor and poor for involving family members/caregivers in care. The mean rating for OTs was 3.5 (fair), PTs was 3.4 (fair), and SLPs was 3.5 (fair). For doctors mean rating was 3 (fair) and for nursing 3.2 (fair). All providers received poorer ratings for involving family in care. See Figure 8.5 for distribution of ratings across providers.

Figure 8.5. Percent distribution of ratings per provider type for involving family members in care upon discharge (mCARE-TBI question 5).

Question 6 from the mCARE-TBI asks, How were healthcare providers at really listening… (giving you time to fully describe your concerns in your own words)? All healthcare providers overall obtained majority of ratings between good and very good for
listening. OTs, PTs, and SLPs, had slightly higher percentages of responses for very good and good compared to doctors and nursing. This trend was also identified through mean ratings. Mean rating for OTs was 4 (good), for PTs was 4.2 (good), and for SLPs was 4.3 (good). Mean rating for doctors was 3.5 (fair) and for nursing was 3.6 (fair). Comparison of means indicates therapists were better than doctors and nurses at really listening. A statistical comparison will be conducted to determine significance of this difference. See Figure 8.6 for distribution of ratings across providers.

Figure 8.6. Percent distribution of ratings per provider type for really listening (mCARE-TBI question 6).

The mCARE-TBI scale question 7 asks, How were healthcare providers at showing care and compassion… (seeming genuinely concerned, treating you as a competent individual)? OTs, PTs, and SLPs obtained approximately 80-85% of ratings between good and very good. For doctors, approximately 57% of ratings were between good and very good. For nurses, approximately 61% of ratings were between good and
very good. Mean ratings for both OTs and PTs was 4.3 (good), as were SLPs at 4.4
(good). The mean rating for doctors was 3.5 (fair) and for nursing was 3.7 (fair). Again,
therapists were better than nurses and doctors at showing care and compassion as
demonstrated through higher overall mean ratings. A statistical comparison will be
conducted to determine significance of this difference. Figure 8.7 depicts distribution of
ratings across disciplines.

Figure 8.7. Percent distribution of ratings per provider type for showing care and
compassion (mCARE-TBI question 7).

Question 8 from the mCARE-TBI scale asks, How were healthcare providers at
being positive… (having a positive approach and a positive attitude)? Again, OTs, PTs,
and SLPs, obtained approximately 75-80% of ratings between good and very good. For
doctors, approximately 56% of ratings were between good and very good. For nursing,
approximately 54% of ratings were between good and very good. Doctors obtained the
highest number of ratings (28%) between poor and very poor. Mean rating for OTs was 4 (good), for PTs was 4.1 (good), and for SLPs was 4.3 (good). For doctors, mean rating was 3.4 (fair), while nursing mean rating was 3.6 (fair). Based on mean ratings, therapists were better than nurses and doctors at being positive. A statistical comparison will be conducted to determine significance of this difference. See Figure 8.8 for distribution of ratings across providers.

Figure 8.8. Percent distribution of ratings per provider type for being positive (mCARE-TBI question 8).

The mCARE-TBI scale question 9 asks, How were healthcare providers at formally acknowledging the consequences of your TBI… (validating symptoms reported, discussing severity clearly)? All provider types received higher percentages of ratings of poor to very poor in response to this question in comparison to the responses from other questions. Nursing obtained approximately 32% of ratings between poor and very poor. OTs, PTs, and SLPs obtained approximately 16-22% of ratings between poor and very poor.
poor. Doctors obtained the highest percentage of ratings between poor and very poor, approximately 35%. The mean rating for OTs was 3.7 (fair), for PTs was 3.9 (fair), and for SLPs was 3.9 (fair). For doctors, the mean rating was 3.2 (fair) and for nursing it was 3.3 (fair). All are in the fair range, although therapists were in the high-fair range and doctors and nurses are in the low-fair range, as is evident through means. See Figure 8.9 for distribution of ratings across disciplines.

Figure 8.9. Percent distribution of ratings per provider type for acknowledging the consequences (mCARE-TBI question 9).

Question 10 from the mCARE-TBI scale asks, How were healthcare providers at treating symptoms and concerns related to TBI… (providing information, treating symptoms, providing contact information to schedule appointments)? For OTs, PTs, and SLPs approximately 70-85% of ratings were between good and very good. For doctors, only 54% of ratings were between good and very good, and 30% of ratings were between
poor and very poor. Similarly, for nursing, only approximately 55% of ratings were between good and very good and 22.5% of ratings were between poor and very poor. This trend was again reflected in mean ratings. The mean rating for OTs was 4.0 (good), for PTs was 4.2 (good), and for SLPs was 4.4 (good). For doctors, the mean rating was 3.4 (fair) and for nursing it was 3.5 (fair). Comparison of means indicates therapists are better than doctors and nurses at treating symptoms and concerns. A statistical comparison will be conducted to determine significance of this difference. See Figure 8.10 for distribution of ratings across disciplines.

Figure 8.10. Percent distribution of ratings per provider type for treating symptoms and concerns (mCARE-TBI question 10).

The mCARE-TBI scale question 11 asks, How were healthcare providers at collaborating with you in your treatment plan…(having an active role in treatment plan, addressing personal values and goals, individualizing plan for treatment)? Doctors and
nursing again had the highest percentages of ratings between poor and very poor. Doctors obtained approximately 33% of ratings between poor and very poor. Nursing obtained approximately 23% of ratings between poor and very poor. However, OTs, PTs, and SLPs, also had slightly higher percentages for poor and very poor in comparison to the responses from other questions. SLPs and PTs had approximately 10% of ratings between poor and very poor, and OTs had approximately 16% of ratings between poor and very poor. The mean rating for OTs was 3.9 (fair, approaching the good range), for PTs was 4.0 (good), and for SLPs was 4.1 (good). For doctors, the mean rating was 3.3 (fair) and for nursing it was 3.5 (fair). Again, therapists were better than doctors and nurses at collaborating with the patient during the treatment plan. A statistical comparison will be conducted to determine significance of this difference. See Figure 8.11 for distribution of ratings across disciplines.

Figure 8.11. Percent distribution of ratings per provider type for collaborating with you (mCARE-TBI question 11).
Qualitative Findings

While the mCARE-TBI scale (Spreitzer & Hoepner, 2019) provided information about overall experience, participants were also provided an opportunity to identify and describe specific particularly positive experiences and particularly negative experiences. The responses to these follow-up questions about particularly good and bad experiences were qualitatively coded.

Qualitative analyses of the online, Qualtrics survey regarding perceptions of acute, transitional, and chronic care identified three main positive perceptions (interactional skills of providers, provided specific supports, and effective collaboration) and three main negative perceptions (problematic interactions, failure to provide specific supports, and limitations to services). Several of these main themes were present across the continuum of recovery. Note that distribution of positives and negatives within acute, transitional, and chronic care settings does not indicate a weighting towards overall positive or negative perceptions.

Within the acute care context, two subcategories (good relationships and skilled and caring providers) were identified related to positive interactional skills of providers. Three subcategories (providing awareness and insight, specific TBI knowledge/research, and providing appropriate referrals) were identified within provided specific supports and services. Three subcategories (lack of collaboration, lack of necessary referrals, and lack of family involvement/education) were identified related to failure to provide specific supports and services. Within the category of
limitations to services, two subcategories were identified (not enough services and insurance issues). See Table 7.1-7.2 for distribution of acute care categories, subcategories, and exemplars.
Table 7.1 Acute care positives.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Exemplars</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interactional skills of providers</td>
<td>Good relationships</td>
<td>“Doctors made me feel included and as though I was a regular person: Therapists tailored rehab to my interests if possible”</td>
</tr>
<tr>
<td></td>
<td>Skilled and caring providers</td>
<td>“(Specific provider name) was kind and also before doing the procedure (hematoma) he told me what was happening. He also did follow-up visit with me when I was in the hospital”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I’m told one nurse would come in on his days off and clean my room. Another doctor bought me Red Lobster when I was not speaking and said “Red Lobster”</td>
</tr>
<tr>
<td>Provided specific supports and services</td>
<td>Providing awareness and insight</td>
<td>“They provided insight and awareness of the TBI and my perception of where I was and how I interacted with others.”</td>
</tr>
<tr>
<td></td>
<td>Specific TBI knowledge/research</td>
<td>In regards to particularly good providers: “Only my physical therapist who did research and my eye doctor who has also studied the brain and spine”</td>
</tr>
<tr>
<td></td>
<td>Providing appropriate referrals</td>
<td>“Doctors who had experience with TBI’s were great”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Multiple testing, multiple doctors they are the ones that saw what I need and contacted the proper rehab”</td>
</tr>
<tr>
<td>Categories</td>
<td>Subcategories</td>
<td>Exemplars</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Problematic interactions</td>
<td>Not listening</td>
<td>“Refusal to listen to full symptoms focused only on one of the three places of impact I took to the head and brain”</td>
</tr>
<tr>
<td></td>
<td>Not providing opportunity for clarification</td>
<td>“ER doctor bombarding with multiple questions, did not allow time for me to answer or ask clarification on what he was asking, I got very confused and cried a lot”</td>
</tr>
<tr>
<td></td>
<td>Disrespectful and demeaning interactions</td>
<td>“Physiatrist did not treat myself with respect. He did not listen, stated some very negative comments about healing and my future”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“The only thing I remember from 10 days at (specific facility) was this nurse leaning over me and saying you have a diaper on use it”</td>
</tr>
<tr>
<td></td>
<td>Discounting and dismissing challenges</td>
<td>“My TBI was brushed off as a minor concussion- a week later when all the symptomology showed up it was only at the urging of the doctor who understood TBIs that action was taken- however, when no brain bleed was found at the hospital- I was sent home with a diagnosis of severe migraine- still missing the problem”</td>
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<tr>
<td></td>
<td></td>
<td>“Doctors, especially neurologists, were arrogant and dismissive of my symptoms. The longer my symptoms persisted, the more annoyed they were”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“One doctor actually minimized a leg discrepancy saying, “lucky to have survived”</td>
</tr>
<tr>
<td></td>
<td>Failure to provide specific supports and services</td>
<td>Lack of collaboration with patient “TBI specialist wouldn’t even look into care options that would help me continue to be able to breastfeed my newborn. Just wanted to push pills at me and tell me to come back 3 months later”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of necessary referrals “It would have been good to have more mental health treatment to cope with this transition”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of family involvement/education “I was in temporary traumatic amnesia for a week, so I do not remember anything. But, the hospital staff never notified anyone that I was even in the hospital, which is pretty awful care”</td>
</tr>
<tr>
<td>Limitations to services</td>
<td>Not enough services</td>
<td>“I can’t really remember being in the hospital. I just know I shouldn’t have been released as soon as I was”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“In the ER they did no testing or questioning in regards to a TBI.”</td>
</tr>
<tr>
<td></td>
<td>Insurance issues</td>
<td>“The doctor who discharged me was worthless but demanded payment because he billed the insurance company before my deductible was met by the hospital”</td>
</tr>
</tbody>
</table>
Analysis of transitional care perceptions identified three subcategories (therapeutic alliance, fully explaining things/providing information and insight, and care and compassion) related to positive interactional skills of providers. Five subcategories (working as a team and coordinating care, involving family, individualizing plan of care, follow-ups and referrals, and group therapy) were identified within provided specific supports and services. Two subcategories (condescending interactions and dismissal of symptoms/not listening) were identified related to problematic interactions. Within the category of failure to provide specific services, six subcategories were identified (lack of follow-ups and referrals, discharge timing issues, inadequate education, not involving family, lack of support, and lack of training in TBI). Two subcategories (insurance issues and lack of availability of necessary services) were identified within the category limitations to services. See Table 8.1-8.2 for distribution of transitional care categories, subcategories, and exemplar.
<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Exemplars</th>
</tr>
</thead>
</table>
| Interactional skills of providers  | Therapeutic alliance (doing the right things to help me get better) | “The local workers comp doctor and speech therapist were probably my best advocates through my experience as they knew what my baseline had been and worked hard to find ways to help me regain all I could- I had a lot of difficulty accepting my new normal”  
“The psychologist was most helpful in guiding me to set realistic goals and make painful, but necessary changes with my lifestyle to make returning home possible + successful” |
|                                    | Fully explaining things/providing information and insight | “My concussion specialist is the only doctor that thoroughly explains why I’m, feeling the way I have been after the injury and maps out every detail of the healing process”  
“Helped me gain insight post-rehabilitation as I began to fail at many things in life” |
|                                    | Care and compassion                                     | “The neurosurgeon was very communicative and compassionate”  
“One aide just sat with me when I was visiting my home from the hospital. Means a lot he would just sit there while I soaked in being home” |
| Provided specific services and supports | Working as a team and coordinating care                 | “All my therapists in my outpatient unit meet weekly as a team to consult each other regarding my progress and challenges. This REALLY helped coordinate my care” |
|                                    | Involving family                                         | “Everyone provided great information so that my family could help me get home and transition and know what to do to help me”  
“My wife encouraged to attend all my therapy sessions so that the care she provided at home would be consistent with the care provided at rehab” |
|                                    | Individualizing plan of care                             | “All involved collected specific information about my home, such as the path of travel, the way I was getting home, who would be around for what kinds of caregiving, what providers there would be at home, the plan of care, and the continuity of care” |
|                                    | Follow-ups and referrals                                 | “Excellent from rehab and even did follow-up phone calls and visits” |
|                                    | Group Therapy                                           | In regards to positive interactions, “OT Group Therapy” |
Table 8.2. Transitional care negatives.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Exemplars</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problematic interactions</td>
<td>Condescending interactions</td>
<td>“He ignored new symptoms, talked down to me and refused to answer 2 questions that reading my file over quickly could have resolved”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“When I had a seizure that left me paralyzed I was treated like I was lying or faking for attention. They also spoke over me, not to me, and asked my family questions rather than me”</td>
</tr>
<tr>
<td></td>
<td>Dismissal of symptoms/not listening</td>
<td>“My statements were dismissed because “I looked fine” and can compensate for limitations”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I was told to just deal with it and screamed at by alleged professionals “why aren’t you better?” They recited repeatedly time rest sleep and believed that was all it would take to heal me”</td>
</tr>
<tr>
<td>Failure to provide specific supports and services</td>
<td>Lack of follow-ups and referrals</td>
<td>“It was left up to me to make sure I received treatment after the hospital”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I felt as though I was lost in the cracks until I started having seizures”</td>
</tr>
<tr>
<td></td>
<td>Discharge timing issues</td>
<td>“All I was told was if I didn’t feel okay in the next few days I could follow-up with my primary doctor, I was released the same night as the accident”</td>
</tr>
<tr>
<td></td>
<td>Inadequate education</td>
<td>“Told to “rest and reduce my stress” then I’d be fine. What an ignorant misdiagnosis lacking helpful instructions to help me recover”</td>
</tr>
<tr>
<td></td>
<td>Not involving family</td>
<td>“My discharge at the last hospital I stayed at did NOT provide any information to my caregiver of what to expect. My caregiver took me to the mall- the crowds and the noise &amp; the lights were overwhelming to me”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“They were not informative to my parents who were there as I was unable to function”</td>
</tr>
<tr>
<td></td>
<td>Lack of support</td>
<td>“No after care information was provided. I was life flighted, unconscious, from TBI 1 and told to go home to rest. Insane lack of support”</td>
</tr>
<tr>
<td></td>
<td>Lack of training in TBI</td>
<td>“In my experience, most doctors are pretty clueless about brain injuries”</td>
</tr>
<tr>
<td>Limitations to services</td>
<td>Insurance issues</td>
<td>“All were concerned with their own liability and billing concerns. Further, I was being denied care by the workers comp system”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“One therapist did say we were looking at months of rehabilitation. Nice joke when our insurance company wouldn’t pay for any post-trauma therapy”</td>
</tr>
<tr>
<td></td>
<td>Lack of availability of necessary services</td>
<td>“Most of this is because there isn’t much local to the town”</td>
</tr>
</tbody>
</table>
In analyses of chronic care perceptions, seven subcategories (compassion, empathy, and understanding, treating the “whole” person, explained rationale for services, invested in patient progress and well-being, truly listening, honesty, and attitude) were identified related to positive interactional skills of providers. Six subcategories (support groups, provided specific strategies and information, helped foster insight and awareness, addressing physical symptoms, TBI specific knowledge/understanding, and obtaining necessary mental health services) were identified within provided specific supports and services. Under the category effective collaboration, two subcategories were identified (collaboration among providers and positive experience overall). Two subcategories (dismissal of symptoms-discounting, ignoring, not fully listening and negative provider attributes- uninterested, arrogant, annoyed, and rushed) were identified related to problematic interactions. Three subcategories (lack of support, lack of collaboration with the patient and misaligning values, and lack of training/knowledge in TBI) were identified related to failure to provide specific supports and services. Within the category of limitations to services, one subcategory was identified (expenses associated with services/insurance issues). See Table 9.1-9.2 for distribution of chronic care categories, subcategories, and exemplars.
<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Exemplars</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interational skills of providers</td>
<td>Compassion, empathy, and understanding</td>
<td>“Only the one neuro assured me that I did not have to accept being “less capable” and said she understood how frustrating it must be to go from being a rocket scientist to barely getting through the day”</td>
</tr>
<tr>
<td></td>
<td>Treating the “whole” person</td>
<td>“The doctors would still and do listen to me and treat me like a human”</td>
</tr>
<tr>
<td></td>
<td>Explained rationale for services</td>
<td>“My physical therapist at the Neuro and Headache Center is wonderful in listening and explaining things to me in ways I understand”</td>
</tr>
<tr>
<td></td>
<td>Invested in patient progress and well-being</td>
<td>“He is extremely attentive, helpful and kind, never did I feel rushed or hurried out”</td>
</tr>
<tr>
<td></td>
<td>Truly listening</td>
<td>“The key element in my treating doctor, physical, speech, and massage therapist was- they listened”</td>
</tr>
<tr>
<td></td>
<td>Honesty</td>
<td>“I had numerous good interactions with professionals who really listened”</td>
</tr>
<tr>
<td></td>
<td>Attitude</td>
<td>“The EMDR therapist has learned about TBI from me. From the start she told me she hadn’t worked with someone in my particular situation”</td>
</tr>
<tr>
<td>Provided specific supports and services</td>
<td>Support groups</td>
<td>“TBI Group- excellent interactions with people that have TBI’s. We share our common experiences and learn from one another what works and what doesn’t”</td>
</tr>
<tr>
<td></td>
<td>Provided specific strategies and information</td>
<td>“I now know how to control pain and what exercises I am able to do and can think/read much better with vision”</td>
</tr>
<tr>
<td></td>
<td>Helped foster insight and awareness</td>
<td>“The Speech Language and Occupational Therapist were most in tune with my condition and also offered the most active ways to get better, through exercises”</td>
</tr>
<tr>
<td></td>
<td>Addressing physical symptoms</td>
<td>“Speech therapy was the best person that actually understood and believed all symptoms”</td>
</tr>
<tr>
<td></td>
<td>TBI specific knowledge/understanding TBI</td>
<td>“PT and Neuro-Optometrist post rehabilitation worked with me collaboratively to diagnose the vision and physical impacts after 17 years post brain injury”</td>
</tr>
<tr>
<td></td>
<td>Obtaining necessary mental health services</td>
<td>“About a year and 1/3 after my brain injury, I knew I needed help or I was going to kill myself. I went to a local mental health clinic. I started talking to a counselor. I do not remember anything that really happened with the counselor, but talking to someone was very beneficial”</td>
</tr>
<tr>
<td>Effective Collaboration</td>
<td>Collaboration among providers</td>
<td>“My PT and NP work with me also collaborate well with my primary doctor”</td>
</tr>
<tr>
<td>Positive experience overall</td>
<td></td>
<td>“Everyone I have encountered has been exceptional”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I had an OUTSTANDING TEAM of care”</td>
</tr>
</tbody>
</table>
Table 89.2. Chronic care negatives.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Exemplars</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problematic interactions</td>
<td>Dismissal of symptoms-discounting, ignoring, not fully listening</td>
<td>“Neurologist discharged me after 5 minute visit because I could carry a conversation with him. Even though I was experiencing other symptoms”&lt;br&gt;“Because my deficits weren’t so apparent or severe, sometimes I feel I was brushed off-meanwhile they were severe to me”&lt;br&gt;“One doc told me “you’re still smarter than most people I see”. The implication being that I was just complaining and needed to get over it”</td>
</tr>
<tr>
<td></td>
<td>Negative provider attributes-uninterested, arrogant, annoyed, rushed</td>
<td>“Doctors are limited to extremely short visits which is frustrating. Also, they get irritated if drugs they put me on don’t work or cause side effects”&lt;br&gt;“Initially had a great podiatrist that worked with the PT, but he turned sour later on and I no longer see him since he tends to blame things on me due to having had a brain injury. This was what I had initially perceived as a professional relationship, but no longer”</td>
</tr>
<tr>
<td>Failure to provide specific supports and services</td>
<td>Lack of support</td>
<td>“For the most part I felt like I was on my own. I figured out a plan to get back to being comfortable driving again. I figured out ways to ease back into work and have founds ways to work around my new shortcomings”&lt;br&gt;“After one year, unless I searched something on my own, I did not receive services that I needed”&lt;br&gt;“I asked my neurologist about what I could do for future treatment, as I knew I was not up to par. I told him I felt as we were dropped like hot potatoes. All he did was grin at me”</td>
</tr>
<tr>
<td></td>
<td>Lack of collaboration with the patient and misaligning values</td>
<td>“TBI specialist wouldn’t even look into care options that would help me continue to be able to breastfeed my newborn. Just wanted to push pills at me and tell me to come back 3 months later”&lt;br&gt;“Too many specialists untrained in TBI- both symptom causes and care to heal”&lt;br&gt;“I have had bad interactions with a plethora of other PT’s, vision experts, and primary care physicians due to them not understanding brain injury”</td>
</tr>
<tr>
<td></td>
<td>Lack of training/knowledge in TBI</td>
<td>“My needs do not matter. Still battling for help. All that matters is the insurer doesn’t want to pay”</td>
</tr>
</tbody>
</table>
Across all points of service in care, participants reflected on both positive and negative experiences with specific facilities, specific types of providers (e.g., doctors, nurses, speech therapist, occupational therapists, physical therapists, etc.), and specific providers (e.g., referred to a provider by name). Furthermore, certain subcategories were identified as positive when present and negative when absent. For example, specific TBI knowledge/research was identified as positive in the acute care phase. However, lack of training/knowledge in TBI was identified as a negative within the chronic care phase as it related to providing specific supports and services. Specific subcategories were present across all phases of recovery. Discounting and dismissal of symptoms to some degree was present across acute, transitional, and chronic phases of recovery.
Part Two: Semi-Structured Interviews

Participants

A total of five interviews were reviewed for initial data analysis. All five of the individuals sustained mild TBIs. All five of the participants indicated no aphasia and reported private health insurance. Four out of the five participants highest level of education was an advanced degree, while the fifth participant’s highest level of education was a 4-year college.

Additional personal demographic variables are displayed in table 7 and injury-related demographics are displayed in table 10.

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Time post-onset</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Race</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>50; 4</td>
<td>8; 11</td>
<td>F</td>
<td>Non-Hispanic</td>
<td>White</td>
</tr>
<tr>
<td>P2</td>
<td>53; 8</td>
<td>1; 4</td>
<td>F</td>
<td>Non-Hispanic</td>
<td>White</td>
</tr>
<tr>
<td>P3</td>
<td>67; 4</td>
<td>15; 3</td>
<td>M</td>
<td>Non-Hispanic</td>
<td>White</td>
</tr>
<tr>
<td>P4</td>
<td>65; 6</td>
<td>5; 0</td>
<td>M</td>
<td>Non-Hispanic</td>
<td>White</td>
</tr>
<tr>
<td>P5</td>
<td>44; 10</td>
<td>5; 6</td>
<td>F</td>
<td>Non-Hispanic</td>
<td>White</td>
</tr>
</tbody>
</table>

Injury severity related demographics are displayed in Table 11. As is displayed in table 11, one participant was unsure of severity, the responses to the other self-check questions were utilized to determine the severity for P3. Many individuals with mild traumatic brain injuries self-reported experiencing more than 7 days of PTA, which is inconsistent with the definition of mild TBI. However, for the purposes of this study to
determine severity level, recall only two of the self-check responses needed to be consistent with defined characteristics of mild TBI. Thus, even though many participants responded inconsistently to the question regarding PTA, the responses to the other self-check responses were consistent with mild TBI. Additionally, while P2 reported moderate severity for TBI, the responses to the self-check responses were consistent with a mild TBI and thus this participant was classified as mild.

Table 11. Injury severity related demographics.

<table>
<thead>
<tr>
<th>Patient</th>
<th>Self-reported severity</th>
<th>GCS: LOC: Coma duration:</th>
<th>PTA:</th>
<th>LOHS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>mild</td>
<td>14-15 0-30 min Not in a coma</td>
<td>More than 7 days</td>
<td>Not hospitalized or n/a</td>
</tr>
<tr>
<td>P2</td>
<td>moderate</td>
<td>Unsure or n/a 0-30 min Not in a coma</td>
<td>More than 7 days</td>
<td>Hospitalized 8 days or more</td>
</tr>
<tr>
<td>P3</td>
<td>unsure</td>
<td>Unsure or n/a 0-30 min Not in a coma</td>
<td>More than 7 days</td>
<td>Hospitalized 1 day or less</td>
</tr>
<tr>
<td>P4</td>
<td>mild</td>
<td>Unsure or n/a 0-30 min Not in a coma</td>
<td>More than 7 days</td>
<td>Hospitalized 6-7 days</td>
</tr>
<tr>
<td>P5</td>
<td>mild</td>
<td>Unsure or n/a 0-30 min Not in a coma</td>
<td>No PTA</td>
<td>Not hospitalized</td>
</tr>
</tbody>
</table>

Notation: LOC = loss of consciousness, LOHS = length of hospital stay

Etiology for these five participants included fall (n=2) and motor vehicle accident (n=3). Follow-up care received ranged from only one-week follow-up, to follow-up more than 1-year post-injury. Two participants selected receiving follow-up care at 1 week, 1 month, 6 months, 1 year, and more than 1-year post-injury.
Quantitative Findings

In order to evaluate the results of the SPRS-2, mean scores were calculated. There are three domains evaluated on the SPRS-2: Work and Leisure, Relationships, and Living Skills. Mean scores for the total score as well as for each domain score were determined. The mean scores can be related to original descriptors and also correspond directly to the same scale utilized by participants. The scale ranges from 0 to 4. On this scale, 0 is indicative of extreme change, 1 is indicative of a lot of change, 2 is indicative of moderate change, 3 is indicative of a little change, and 4 is indicative of no change at all. The mean domain scores and total mean score obtained for each participant are displayed in Table 12. Mean ratings for Work and Leisure across all five participants was 2.1 (SD = 1.13) indicating moderate perceived change. Mean ratings for Relationships across participants was 2.88 (SD =1.03) indicating moderate to a little perceived change. Mean ratings across participants for Living Skills was 3.35 (SD = 0.80), indicating a little to no perceived change. Finally, mean total scores across participants was 2.78 (SD = 0.97), indicating moderate to a little perceived change.
Table 12. SPRS-2 participant mean scores.

<table>
<thead>
<tr>
<th></th>
<th>Work and Leisure</th>
<th>Relationships</th>
<th>Living Skills</th>
<th>Overall Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>2.75 3.5 4</td>
<td></td>
<td></td>
<td>3.42</td>
</tr>
<tr>
<td></td>
<td>Moderately to a little</td>
<td>A little to not at all</td>
<td>Not at all</td>
<td>A little to not at all</td>
</tr>
<tr>
<td>P2</td>
<td>3 3.4 4</td>
<td></td>
<td></td>
<td>3.46</td>
</tr>
<tr>
<td></td>
<td>A little</td>
<td>A little to not at all</td>
<td>Not at all</td>
<td>A little to not at all</td>
</tr>
<tr>
<td>P3</td>
<td>1 2.5 2.75 3.5</td>
<td></td>
<td></td>
<td>2.08</td>
</tr>
<tr>
<td></td>
<td>A lot</td>
<td>Moderate to a little</td>
<td>Moderately to a little</td>
<td>Moderately to a little</td>
</tr>
<tr>
<td>P4</td>
<td>3 3.75 3.75 3.5</td>
<td></td>
<td></td>
<td>3.5</td>
</tr>
<tr>
<td></td>
<td>A little</td>
<td>A little to not at all</td>
<td>A little not at all</td>
<td>A little to not at all</td>
</tr>
<tr>
<td>P5</td>
<td>0.75 1.25 2.25 1.42</td>
<td></td>
<td></td>
<td>1.42</td>
</tr>
<tr>
<td></td>
<td>Extreme to a lot</td>
<td>A lot to moderately</td>
<td>Moderately to a little</td>
<td>A lot to moderately</td>
</tr>
</tbody>
</table>

Mean (SD): 2.1 (1.13) 2.88 (1.03) 3.35 (0.80) 2.78 (0.97)

**Qualitative Findings**

Statement acknowledging potential for bias. While the analysis of semi-structured interviews was completed across multiple points of time to increase validity and objectivity, it is necessary to acknowledge the potential for bias. The primary researcher had prior clinical experiences with individuals in TBI support groups (including a university-based group for individuals with mild to moderate impairments due to brain injury, a community-based group for individuals with severe impairments due to brain injury, and a community-based group for individuals with mild to moderate impairments...
due to brain injury), treated individuals with TBI in speech-language therapy sessions, and has some personal experience with knowing individuals with TBIs. These prior experiences have the potential to lead to bias. However, to minimize personal bias, additional efforts were made including iterative analysis procedures to support code stability and reviewing transcripts/codes closely with primary research faculty mentor.

Phenomenological research procedures were utilized for analysis of semi-structured interviews. These specific procedures are outlined below. Throughout the description of these procedures, first person language (i.e., I, me, my) will be utilized. First person language is the convention most commonly used for reporting phenomenological outcomes, and therefore are used in the descriptions within this study.

**Phenomenological analysis:** Phenomenological analysis procedures previously developed by Hooson et al. (2013) and Brown et al. (2010) were utilized and slightly modified. I engaged in close reading of the interview transcripts, identifying significant statements as I read but more broadly taking in the story line of each participant as it emerged. Shared close reading with my research mentor allowed for validation and affirmation of the initial ideas I derived from the content. Themes were derived out of clusters of meaning within significant statements by each of the participants. Highlighting key statements identified unique experiences and perspectives of individual participants, as well as identifying commonalities across participants. This process shaped the structure for reporting these results, which include case descriptions and group themes. Collectively, those individual and common group themes generated a dense, textural description of
what the participants experienced. Structural description regarding how the participants experienced the phenomenon was generated by addressing how contexts (acute, transitional, and chronic care settings) and the people they encountered (therapists, physicians, care staff) influenced their perceptions. Finally, my own experience influenced the way these interviews were processed, as is identified in the bias statement above.

**Case descriptions**

Fictitious names were identified in order to retain a sense of humanity among each of the interviewees. Descriptions of each of those interviewees follows.

Janet is a 44-year-old female who experienced her brain injury five and a half years ago. Approximately six weeks after her initial injury, she sustained a second brain injury. Prior to her injury, Janet was a nurse. Although she attempted to return to that position, the effects of her TBI led to some significant challenges. While her manager offered to hold her job for her, her manager recommended that she focus on her recovery full-time instead of continuing to work. Ultimately, Janet’s job was too demanding and there were a lack of transition supports for promoting success in completion of her job post-injury. Currently, she works per diem completing administrative tasks for her previous manager. She was married prior to her TBI but that relationship ended a couple of months after her brain injury. Each of these vocational and social factors are relevant to Janet’s perceptions of healthcare across acute, transitional, and chronic phases. Janet had good support from family, including her former spouse, during the acute phase of her
recovery. As she transitioned from rehabilitation to return to work and duties at home, her relationship began to encounter increasing struggles. This paralleled her frustrations with healthcare in the chronic phase. She felt disregarded and disenfranchised, as physicians told her she was fine and should move on, while giving her mixed messages about the severity of her injury and ongoing consequences. Even though she had professional knowledge about brain injury, she remarked that knowledge was discounted by her physicians. This resulted in additional frustration as a previous clinician focused on providing quality patient care.

Alyssa is a 50-year-old female who sustained her TBI eight years ago. At the time of her injury, she was working as an engineer and following her recovery, she returned to her same job. While her vocation remained the same post-injury, other psychosocial aspects of her life changed including leisure and hobbies. For example, she started avoiding going to the gym due to the noise and instead works out at home. She also reported experiencing increased fatigue negatively impacting previous leisure activities and household responsibilities. While she had good support from family, she felt she needed to figure out how to adjust to post-injury life on her own. Following initial care, she was given very minimal support and information on who to follow-up with. When her post-TBI symptoms became unbearable, she attempted to contact providers on her own to assist in management. However, she experienced further breakdowns in the follow-up process as doctors would not return her phone calls resulting in her increased frustrations. She also described the lack of willingness of a specific healthcare provider to listen and collaborate with her to develop a treatment plan. Her thoughts were
disregarded by the provider entirely and she eventually agreed to his plan in hopes to get additional treatment. Her frustrations made her skeptical of other providers, even providers with whom she later had positive experiences. Overall, Alyssa received minimal information in urgent care following her injury, requiring her to create her own plan of care for follow-up. Even after follow-up with her doctor, she was not given any information on what to do or expect resulting in the need to continue to figure it out on her own. In her experience, her recovery extended into the chronic phase, as many providers told her to wait for improvement to occur rather than providing her any specific supports. She did not feel that her symptoms improved until about a year after her injury when she saw a different neurologist that provided her with supports. While she ended up eventually setting up follow-up care, she had wished she knew more information about what to expect and what to do post-injury, rather than needing to figure it all out on her own.

Hailey is a 53-year-old female who sustained her brain injury approximately two years ago. Her husband was also present for the interview and shared additional information about Hailey’s healthcare experience. At the time of the injury she worked full-time as a school media specialist. Post-injury she needed to gradually build up to working full-time again. Her employer provided her with an additional planning day by reducing the number of students she needed to see. With these supports in place, she was able to return to working full-time. For Hailey, she had a great support system consisting of her friends and family throughout the recovery process. She started a new hobby post-injury allowing her to extend her social network. During the acute care phase, Hailey felt
well-supported by her healthcare providers and she received excellent care. However, upon discharge they struggled to obtain follow-up services. Her husband stated they were “bounced around” between several places and for two to three months they had difficulty figuring out where to go. Hailey and her husband needed to advocate for her follow-up needs. During rehabilitation, she felt that she did not receive the same level of attention in acute care and that healthcare providers were not as specialized in brain injury. Hailey and her husband often felt confused with the information received while in this setting. After the rehabilitation phase, Hailey still continued to need additional care. Hailey and her husband again struggled to set-up appointments with providers due to availability issues. Her husband stated that an appointment for a specialist (neurologist) needed to be set-up six to eight months in advance. However, Hailey needed to see someone much sooner and could not wait that time period. Upon finally seeing a neurologist, she felt increased frustration and stated she was essentially told she would never get better. This false timeline for her recovery further resulted in frustration towards healthcare as she approached the chronic phase of recovery.

After this negative experience, she eventually was able to follow-up with a neurosurgeon that she originally saw in the ICU and continues to follow-up with him. Throughout her recovery, Hailey and her husband felt the need to seek other additional services on their own. Overall, Hailey and her husband, did not feel supported during the chronic phase of recovery. There was a lack of coordination of care resulting in increased confusion and frustration. They struggled to obtain follow-up services due to lack of availability of providers. In order to obtain any follow-up services, Hailey and her
husband needed to self-advocate, be perseverant, and rely on personal connections formed to help obtain necessary services. Hailey and her husband wished they had someone that could have helped to coordinate her care and that they would have received more information for long-term supports. They felt that if they had been given access to long-term supports earlier during recovery, she may have been able to make more improvements. However, Hailey and her husband instead needed to find long-term supports including yoga and the TBI support group on their own during the chronic phase of recovery.

Samuel is a 67 year-old-male who sustained his brain injury 15 years ago. At the time of his injury, he was working as a risk manager. At the time of the interview he had retired, but still was managing rental properties. He felt that he would not have been able to return to his previous job post-injury. Overall, there were a lack of transition supports available for him to return to work. Initially after his injury, he needed to figure out how to cope with executive function impairment and increased fatigue resulting in decreased ability to participate in life activities. Samuel had support from his wife and family throughout his recovery. The care he received early on, during his acute phase of recovery, was excellent. He had a doctor who helped coordinate his care and provided information for follow-up services with speech therapy, behavioral therapy, and physical therapy. This transitional support provided by his doctor allowed him to obtain necessary additional services. His positive experiences with healthcare providers were characterized by their willingness to listen, acknowledge the consequences of the TBI, and collaborate with Samuel in his treatment plan. While he had generally positive healthcare
experiences across settings, he reflected on one negative experience with a healthcare provider. He felt that the healthcare provider lacked the awareness of TBI s and did not acknowledge the associated consequences. Not only was Samuel satisfied with his initial care following injury, but stated his long-term care has also been excellent. Shortly after his brain injury, he received information about a local TBI support group from his speech therapist. While he initially felt uncertain about attending the group, he has now been attending the same support group for nearly 15 years. He identified it as one of the best treatments because the other people there truly understand what he is going through. The peer support offered through the group has provided insight into what others have found helpful in coping with life post-TBI. He received information about the group from his speech therapist shortly after his brain injury.

Samuel frequently mentioned the need for adjustments initially after injury. However, due to the time elapsed since his injury, Samuel offered a unique perspective on acceptance of change and increased self-awareness. Even with the time elapsed since injury, Samuel also identified the importance of long-term supports. For Samuel, he was fortunate enough to be provided with information about long-term supports shortly after his injury and still utilizes some of these long-term supports today, including the local TBI support group.

John is a 65-year-old male who sustained his brain injury approximately five years ago. He is retired and stated he retired at the time of his accident. He currently volunteers at the hospital and works a per diem position as a patient observer. Prior to his
injury, he worked as a tax assessor. He stated he was unable to return to work following his injury, likely due to the lack of work transition supports. He is passionate about helping other people with brain injuries through his volunteer work at the hospital as well as working with a state brain injury association. Post-injury he stated his social circle is now larger than prior to his injury and he has had great family support throughout his recovery process. John stated he did not recall anything from his acute hospital stay. However, felt the care he received during rehabilitation was excellent. During his stay, one of his providers, a speech therapist, provided him with information on peer therapy from a textbook. This information inspired him to begin volunteering at the hospital and helping others. While volunteering at the hospital, the staff members frequently ask John to talk to patients because of the perspective he can offer as a TBI survivor. The staff members at the hospital that treated his TBI treat him as an expert in TBI and allow for him to help other patients with his expertise. While his acute and rehabilitation experiences were positive, he felt his follow-up care was less consistent. During interaction with a specific provider, he felt the provider was not paying attention to him. With another provider, he felt he was completely dismissed due to his ability to converse during an appointment with the neurologist, despite other ongoing symptoms. Overall, the primary care doctors he has encountered have lacked the understanding and knowledge for treating TBIs. While he has had negative experiences with certain providers, his positive experiences with providers have allowed him to obtain necessary services even through the chronic phase of recovery. His post-injury life required him to make several adjustments including coping with fatigue and accepting the consequences of the injury.
While each individual had a unique experience within the healthcare setting, commonalities across experiences were also present. Clusters of meaning were derived from significant statements across participants. These common themes were characterized through thematic analysis. This allowed for the individual experience to be considered while also connecting the participants’ experiences to one another through themes.

**Common Themes**

Through phenomenological analysis of transcripts, it was noted that each participant had a rich and unique story to tell. That being said, several common themes were identified across participants. Many participants expressed frustration with the healthcare system and specifically, with the lack of individualized care received. Due to this common theme noted through initial review, it was necessary to thoroughly review each transcript in-depth. As analysis progressed, the importance of each experience and context surrounding these experiences were critical to consider. Across participants, four core themes were identified. Each core theme represents evidence of a preponderance of comments and reflections focused on these ideas.

Core theme 1 - A frustrating and exasperating experience
Following an initial discussion related to describing the experience of TBI within the medical setting, one participant identified feelings of frustration, being dismissed, and the need for self-advocacy throughout the recovery process.

P1 stated, “For me, it was frustrating and exasperating and felt like pretty much either the doctors didn’t listen to what, to when I was saying you know I’m having difficulty with this thing or the other thing. I couldn’t tell whether they just thought I was exaggerating or that I wasn’t trying hard enough to get better, I don’t know.”

P5 stated, “I am so, so disappointed and so enraged. Especially as a clinician myself. Like I wanted to punch these doctors in, in their arrogant little faces”

P2 stated, “Nobody’s following you and saying, you’re getting this care. It’s just kinda up to us to make the appointments and make it happen”

Several other participants reflected on the frustration of the experience, especially, as it related to the lack of supports available to adjust to life post-TBI.

P5 stated in regards to her post-TBI life, “And um, after the injury, it was just, it was decimated. Like when I tell you I have no life, I am not exaggerating. And I’m sure you’ve heard that from other
people because you can’t, you literally cannot do anything. Like you can’t go into a bar cause you can’t tolerate the noise. You can’t drink alcohol. Um, and you, can’t go uh you know, huge hockey fan, so I used to go to hockey games all the time. I had you know season tickets. I’ll probably never be able to go to a hockey game again. Um, so it just, it really, it destroys your life”

In regards to returning to work, P3 stated, “And if I would have went back, I would have ended up getting fired, cause I wouldn’t have been able to do the job”

Many participants identified needing to continuously self-advocate for the services they needed.

P2 stated, “And that was basically a fluke.(P2’s husband)was sitting at one of my physical therapy appointments and they had a, a thing on TV about coming in to see a doctor there so he called the number and he had to talk the people into the situation, what was going on, and then that’s how we got back in. Basically, he had to beg them to take us”

Further reflecting on this experience, P2 explained, “And the reason, I had long term physical therapy, occupational therapy, and speech therapy was because we begged to get back in with the neurosurgeon and he
wrote the prescription for it. Because once I was released from (specific rehab facility), I did not have a prescription for therapy. I could not go to anymore therapy.”

P1 stated, “The pain was unrelenting. I’ve never, I mean never felt anything like that. And I couldn’t get a doctor to call me back”

Several participants independently needed to navigate this process, especially in the chronic phase of recovery.

P1 stated, “I felt like it was kind of up to me, I’m the one who got myself back to, figuring out how to get back to work full-time and find the work arounds”

P2’s husband stated, “It just would’ve been nice to know that there were things like the TBI support group here over by where we live. Uh some other things like that. The yoga thing which has been so good for her. I mean that’s just kinda a new thing that we just kinda stumbled on, that you know, if it, we could’ve, would’ve tried it a year ago, maybe she would’ve gotten better even faster. But we’re slowly putting the pieces together, really getting a really strong program”

P5 stated, “None of them recommended anything. Except go home and rest. That’s it”.
P5 also added she needed to find her own information saying, “On my own I found on social media um, a support group on Facebook. I found one that was just for post-concussion syndrome and then I found one that was for post-concussion syndrome just for nurses”

Core theme 2- Referrals, availability, and following-up with providers

Several participants identified barriers to accessing care including lack of availability of providers and lack of follow-up from providers. This again required perseverance from the individual to obtain necessary services.

One participant, P1, stated, “At one point, I was bed ridden for days, maybe a week or two, I don’t remember, with unbearable headaches. I mean not able to sleep, couldn’t close my eyes cause everything spun. Open my eyes and I’m dizzy and nauseous. The pain was unrelenting. I’ve never felt anything like that. And I couldn’t get a doctor to call me back”

This individual reflected on the extreme pain and discomfort experienced negatively impacting quality of life and ability to participate in daily life for at least a week. Even after this individual called a provider, seeking help, the provider never followed-up with her.
Other participants also reflected on the negative impact on life when providers were not available or did not follow-up to attempt to assist when necessary.

Another participant, P2, and her husband stated, “For when Hailey was in that funky period when we were really struggling, we were trying, and trying, and trying and kept making calls and nobody’s accepting new patients and hey it’d be 6 months”

Others discussed the increased difficulty in management of symptoms when not provided with appropriate referrals.

P5 stated, “I think you’re far enough out that you’re okay. But you know, you could have concussion symptoms for months. He didn’t say go see a neurologist. He didn’t tell me, come in and let me look at you. That was it!”

While for several participants the lack of referrals, availability, and follow-up was associated with increased frustrations and negative perceptions of healthcare, other participants had a different experience. Some participants who received appropriate referrals and follow-up with providers, felt much better supported.

P3 stated, “I would say I was very fortunate early on where I had a good doctor who was able to diagnose the TBI and then point me in
the right directions for follow-up like speech therapy, and behavioral therapy, and physical therapy”

This participant who experienced good follow-up care early on in the process, felt that overall experience within the healthcare setting was generally very positive. Some of the follow-up care services and information he was provided early on even extended to supporting him throughout the chronic phase of recovery.

**Core theme 3- Types of provider interactional styles**

Many participants identified negative interactional styles exhibited by providers. This included being dismissed by providers as well as having symptoms disregarded during interactions.

*General dismissal of symptoms.* Several participants reflected on how providers directly dismissed their symptoms and what they were experiencing.

P5 stated, “Like I went to the best hospitals and saw supposedly the best neurologists. Neurologists know all about post-concussion syndrome and traumatic brain injury. They know nothing. And I even had one of them say to me, you know they all looked at me like I was crazy. They’re like, well we don’t know why you’re not getting better. And I was like, well I hit my head twice in 6 weeks, and the second injury came on top of one that hadn’t even
healed. Like you can explain that to a 5-year-old and they’ll get that”

P5 further expressed her frustration in regards to being dismissed by providers saying, “I think part of it was just this enormous arrogance because they didn’t have any tools to give me. So they were just like in denial. Like because I don’t know how to fix you, this is all in your head you’re imagining this. So it was really demoralizing.”

Another participant stated, “I think I maybe spent maybe spent five minutes with him post discharge and it was... um he was surprised I was able to talk to him and showed me to the door and said, “you’re fine” and uh my wife was like, “woah woah woah, I can look at him and tell when he’s having an off day”. And uh, um he goes, “well we all have those”. And showed me the door.” -P4

Disregarding thoughts on treatment- One participant reflected on how her thoughts on a specific treatment were disregarded. Ultimately, this individual went through with the plan, in hopes that it would allow her to obtain additional necessary treatment to manage symptoms.

“And I went back and said I’ve already had the MRI. Cause he said you have to do the VNG and then do the MRI to, to prove just to make sure there’s nothing physical in your brain that needs to be, you know, like a tumor or whatever. So, I said you know I’ve
done the MRI, I really don’t think I can tolerate the VNG so can I just go ahead and do some vestibular rehab and see if that helps and he insisted that we had to know whether it was central or peripheral vertigo, and he got really um, I’m sorry I’m gonna be really snotty about him he got super butthurt when I said that VNG just sounds really awful, it sounds torturous for the way I feel. I know that I, you know it’s just gonna be awful. He got super upset and offended. Oh my goodness this is so ridiculous. He said that’s not torture, waterboarding is torture and you know I was like wow so you, you’re, you have more empathy for some murderous terrorist than your own patient who has real symptoms ok”. -P1

As is outlined by this specific example, despite the patient explicitly explaining thoughts on a given procedure, the medical provider continued to insist on completion, with little education provided to the participant on importance or necessity for completion of this. Furthermore, in addition to disregarding P1’s thoughts on treatment, lack of empathy for the particular situation was also demonstrated by the provider and identified by this participant. P1 underwent the VNG and again reflected on this experience.

“I went back to him and he said oh it looks like it says it’s central vertigo, I can’t do anything for you good luck. And I said but you said that now that you, now that I’ve done this that you would, I could get, I could get a you know, a referral for therapy. I’ve never sent anyone for physical therapy who says
they have central vertigo. So if I had known, that I would’ve never done the test. I would’ve gone to somebody else.” -P1

Overall, many participants identified lack of collaboration between providers and themselves resulting in increased frustration and misunderstanding.

Another participant identified an attempt to establish a treatment plan with a provider and stated, “And I called my doctor, and I said do I need another CAT scan? Like do I have a brain bleed? Like, I like something’s not right here. Like I can’t get out of bed. I can’t really talk. Like, I, like what is going on? And totally poopooed me and said you know, oh you’re a nurse. You know what the signs of a brain bleed and swelling are. And he said you know, um, I think you’re far enough out that you’re okay. But you know you could have concussion symptoms for months” -P5

As the above exemplars indicate, participants identified, misaligning perspectives between provider and patient resulting in lack of clear communication and ultimately lack of resolution to symptoms experienced by the patient.

In addition to negative interactional styles exhibited by providers, many participants also reflected on positive interactional styles and attributes of providers. This included validating and acknowledging symptoms.
P1 stated, “and then she said no you’re not crazy, yes these are real symptoms and yes there’s I think we can make it better... obviously she, she said, she at least acknowledged that no, that I agree that no this is not normal functioning for you and even a small, uh, like a small hit to your everyday functioning for what you do is a big deal”

In reflecting broadly on positive healthcare providers encountered, P3 stated, “Um yeah, the good, the good ones, and this can be used as a blanket statement, uh, which would encompass speech therapists, the doctor, the neurologist, um the behavioral uh therapists. The, the key thing was all of them listened and acknowledged, and I felt like it was working together.”

While dismissing symptoms was damaging to the relationship with provider, validation and acknowledgement was deeply valued by participants. Participants also valued thorough and caring providers focusing on providing individualized care.

P1 reflected on a positive experience with one of her providers and stated, “And it’s not like she was warm and fuzzy or you know, she was just very thorough, very detailed, very um, like an engineer is what, what I would describe her as”

The importance of individualized care and feeling like the provider was truly invested was also discussed. P3 stated, “I feel extremely fortunate that the doctor that I saw, pointed me in the right direction and, he took a
definite personal interest in, in how I was doing. Probably because he knew me from before, but also just the fact that he’s that kind of a person as a physician. He takes a definite interest in all his patients. So, for me I was lucky”

Core theme 4- Information received about brain injury and what to expect

Several participants identified overall a lack of resources, information, and education provided for TBI. Many participants stated they did not know what to expect and were given minimal amounts of information to truly help the recovery process.

P1 stated, “I wasn’t given any literature or anything of you know, of what to do or what to expect or any of that.”

P2 and her husband explained, “(Specific rehab facility) everything was great, but then once you got released, we really had to struggle, bounced around between a few different practices to really get the follow-up care. Kinda like hey you’re released but you still have traumatic brain injury. So it was like, she still needed, she still need PT so luckily we were, scrambling around and making calls and finally got back into the neurosurgeons office who kinda took back over. But there was like a 2 or 3 month period where we were just kinda struggling to figure out where to go”

Another participant identified the lack of information received and follow-up care as negatively impacting her overall recovery process and stated, “You know, I think
um, if I had been given the proper care, if my doctor hadn’t just blown me off when I called him that day, none of this ever would’ve happened” -P5

False timeline of recovery- Of the information that was provided, for several participants this included a false timeline of recovery and from the perspective of the participants, was inaccurate and ineffective in helping the recovery process.

“They just kinda just said oh just keep waiting, give it 6 weeks, give it 2 weeks, that kinda thing, each time I’d go back. And you know I’d sort of mentally put that date on the calendar thinking okay by then I’ll feel better. And then I’d get to that date and feel no, no better. Sometimes even worse.” -P1

For some, being provided a false timeline of recovery resulted in more confusion. For this participant, after being told she would feel better, occasionally felt even worse. This conflicting information appeared to result in increased frustration for some of the participants.

Another participant and her husband explained the increase in concern when given a false timeline for recovery, “We just kept hearing 6 months, 6 months, 6 months. If you don’t get better in 6 months that’s gonna be it. You know she had made improvement after 6 months. So it kinda freaks ya out. Right, cause that’s a small time period and you
go, oh my God, this is it. But, you know, like I said at that point in time, she couldn’t drive, but now she’s driving. And things have gotten better since after 6 months.”

*Lack of specific information about traumatic brain injury*- One participant reflected on the specific difficulty associated with navigating through a TBI without necessary information and what to expect.

P1 stated wishing to have known, “Maybe just you know what, what kinda symptoms could happen, might happen. What to do if they are happening, who to see. What things you should or shouldn’t do. I mean I just kind of felt like ok well, like every- you know if I’ve been sick or sprained an ankle you just sort of, you know work through it and push past the pain and things like that, so that’s what I thought I should do. So I would go to work or I stopped driving. Like my husband would drop me off at work. I’d feel okay and then, you know an hour later just be miserable but I’d try to push through it cause that’s the only way to get better. And I don’t know that was, it may not have been the right thing to do. I don’t know so, but I wasn’t getting any input or advice on what I should do so, I just kinda made it up as I went along.”
Another participant, P5, expressed the minimal information she had received and stated, “The emergency room doctor was just like yeah go home and take Tylenol and don’t bend down”

Without specific information provided about TBI, many participants were required to figure out what to do on their own. Participants that did receive specific information to support recovery deeply valued this information.

P2 stated healthcare providers involved her husband in explanations of changes occurring and stated, “They basically told my husband what areas I had bleeding in the brain and how that impacted me, at that time. And then over time, I’ve had other MRIs. And then we’ve had meetings about what is still going on in my brain.”

Generally, those who did not receive specific information struggled through the recovery process, especially in the chronic phase of recovery. However, participants provided with specific information again were better supported across all phases of recovery.

P3 stated, “Probably the biggest thing when I went to (Specific facility), the speech therapist, (provider name), had information for me. And then she was the one that pointed me in the direction of the traumatic brain injury support group. In fact, they started it there. So that was excellent from that standpoint.”
P3 further identified the TBI group that he was referred to shortly after his injury as continuing to support him throughout the chronic phase. For him, by being provided information for the group early on in recovery, he was given ongoing access to not only short-term supports, but long-term supports as well.

**Perceptions of healthcare quality across phases of recovery by persons with TBI**

*This is the birds eye view, this is what shapes their experience, overarching experience and context – how the participants experienced the phenomena; following the acute -> transitional ->chronic phases.*

The perspectives expressed by the participants during interviews were shaped by the supports provided across phases of recovery. This included the information provided as it related to follow-up, availability of providers, and the interactional styles of providers. Each of these elements were important and impacted perceptions across all phases of recovery. While each of these elements are key to consider across phases, there are also general trends in each phase.

Through analysis of the transcripts, key concepts from each phase of recovery also emerged. Many participants identified the acute care phase as a very positive experience. In this setting, many individuals had more direct access to specialists such as neurologists. This resulted in participants feeling better supported and that healthcare providers were directly addressing the issues the individual with TBI was having.
However, there was a shift that occurred for many between acute care and the transitional phase of recovery.

During the transitional phase there was no longer the same level of specialized services readily available. Additionally, there was often a lack of coordination of care and inadequate communication between the provider and patient. With a lack of coordination of care during this phase, many participants struggled to adjust to post-TBI life without the proper supports. This included negative impacts on not only health, but vocational and psychosocial aspects of life as well.

After the transitional phase, several participants explicitly identified the lack of support in the chronic phase of recovery. The participant that received information about long-term support, was able to obtain this support and continues to utilize it 15 years post-injury. For the other individuals that did not receive information about long-term community supports, perseverance, self-advocacy, and independent navigation was necessary to obtain additional support for the chronic phase of recovery.
CHAPTER 4

DISCUSSION

The present investigation provides a starting point for considering healthcare perceptions across the acute, transitional, and chronic phases of the recovery continuum for individuals living primarily in the United States. Perceptions of the acute care context are quite positive and generally consistent with past findings (Manskow et al., 2018). Likewise, perceptions of the transitional phase, including problems with communication and planning for discharge, support previous findings (Piccenna et al., 2016; Turner et al., 2008). While other researchers in Australia, Norway, and Finland explored chronic phase perceptions, there is minimal information about healthcare perceptions in the chronic phase within the United States (Andelic et al., 2014; Jourdan et al., 2017; O’Callaghan et al., 2010). As expected, participants reported much more variability and negative perceptions during the chronic phases, thus supporting our initial hypothesis. Additionally, specific areas service-delivery may be improved by providers was also identified. Phenomenological analysis of qualitative interviews also revealed considerable concerns about breakdowns in care during the chronic phases of recovery.

Part One: Survey

*Modified CARE-TBI questionnaire across recovery continuum.*

The mCARE-TBI questionnaire provided specific information about perceptions of healthcare provision across acute to chronic care. Most participants indicated that *overall quality of care in acute, rehab, and long-term care (chronic) settings* was good or very good. This aligns with previous research conducted in Australia by O’Callaghan et al. (2010) indicating most participants were either happy or extremely happy with their
overall healthcare experience. Only approximately 30% of participants identified overall perceptions of acute care as fair (21%) to poor/very poor (10%). Overall acute care setting perceptions identified in this study are consistent with prior research indicating overall satisfaction with acute care was fairly high (Manskow et al., 2018; O’Callaghan et al., 2010). Likewise, about 27% expressed fair (15%) to poor/very poor (12%) ratings in rehab. For the rehabilitation phase or transitional phase, prior research indicates a decrease in overall satisfaction compared to acute care (Piccenna et al., 2016; Turner et al., 2008). This trend was even more severe in the chronic phase, as over 50% reported fair (25.8%) to poor/very poor (25.8%) perceptions of long-term (chronic) care. Past research has documented several unmet needs and a lack of ongoing services in the chronic phase of recovery (Andelic et al., 2014; Heineman et al., 2002; Jourdan et al., 2017; O’Callaghan et al., 2010). The current investigation is among the first studies evaluating these chronic phase perceptions for individuals with TBI across the United States. In comparison to the acute and transitional phases of recovery, perceptions of the chronic phase are slightly more negative based on the current results. Statistical comparisons are planned as a follow-up to examine whether the differences were significant. These results indicate the importance of support for recovery across all phases for individuals with TBI and suggest chronic phase perceptions are more negative than acute and transitional phases of recovery.

Acute care perceptions. Past research has addressed perceptions of healthcare quality within acute care (Manskow et al., 2018; O’Callaghan et al., 2010). The mCARE-TBI findings were consistent with these perceptions. For meeting overall needs in the acute
In the acute care phase, over 75% of reported perceptions of all providers (nursing, OTs, PTs, SLPs, doctors, and other related professions) were good to very good in the acute care context. Mean ratings were almost equivalent across these providers. This is similar to findings by Manskow et al. (2018), indicating high overall satisfaction in the acute care setting and identifying the experience within acute care as the best in comparison to the discharge phase. It is important to consider the potential limitations associated with these acute care perceptions. From a physiological standpoint, many individuals experienced PTA for extended periods of time, thus, may not fully recall all details about the care received in the acute care phase. Additionally, for many individuals the time post-onset, may also add difficulty to accuracy in recall for this phase. However, even if individuals do not fully recall the experience, what is recalled is likely to impact overall attitudes towards healthcare. This study acknowledges perception as reality and thus this positive perception of the acute care phase is still a critical finding. Comparisons of means across providers suggests all providers are pretty good at meeting needs during the acute phase of recovery. Statistical comparisons are planned to objectively evaluate this finding.

**Transitional care (discharge planning) perceptions.** Ratings of healthcare providers in the transitional phase varied more by provider type. For assisting in the transition home, while more than 50% of all providers were rated as good to very good, nearly 50% of nurses and doctors were rated in the fair to poor or very poor range. While mean ratings for therapists (SLPs, OTS, PTs) were good, mean ratings for nurses and doctors were fair. In fact, nearly 25% of nurses and doctors were rated as very poor. This is consistent with prior research describing this phase as difficult with disorganized arrangements (Piccenna
et al., 2016; Turner et al., 2008). However, the current study also provides new information related to specific provider type. It appears that therapists were identified as better than doctors and nurses in assisting with the transition home. Follow-up statistical comparisons are planned to examine whether the differences were significant. It may be possible that training for doctors and nurses is different than the training received by rehabilitation therapists in supporting the transition process for individuals with TBI. However, more research is necessary to determine the validity of this hypothesis.

For explaining things clearly upon discharge, most providers either exceeded or approached 50% of perceptions in the good to very good range, however; all providers had more poor to very poor ratings in comparison to other mCARE-TBI questionnaire responses. Over 55% of doctors were rated as fair (15%) to poor/very poor (40%) in providing clear information at discharge. Likewise, 52% of nurses’ ratings fell in the fair (20%) to poor/very poor (32%) range. Therapies (SLPs, OTs, PTs) were not immune to these ratings either with nearly 18% of their ratings falling in the very poor range. Examining the means suggests that all providers were fairly bad at explaining things clearly upon discharge. Again, follow-up comparisons are planned to examine whether these differences between provider types were significant. While healthcare providers may argue information is being provided upon discharge, the current investigation indicates if this information is being provided it is not retained, and thus does not help adequately support the individual with TBI. Again, this is consistent with previous research indicating during the transitional phase, there is insufficient information and disorganized arrangements when transitioning from hospital to home (Piccenna et al., 2016; Turner et al., 2008).
For involving family members in care, all providers also received higher
percentages of very poor ratings. Approximately 30% to 40% of all provider ratings were
between poor and very poor. Nearly 30% of doctors’ ratings were very poor and 22% of
nurses’ ratings were very poor. For therapists (SLPs, OTs, PTs), approximately 20% of
ratings were very poor, indicating higher very poor ratings for all providers in response to
this question compared to responses on other mCARE-TBI questions. Through
comparison of means, it appears that all providers performed more poorly in involving
family in care. Statistical comparisons are planned to further examine this finding. This is
consistent with previous research which indicated family and caregivers were not
involved in discharge arrangements or decisions about care (Piccenna et al., 2016). While
prior research indicates the critical role family members play in supporting individuals
with TBI, the current research indicates many family members are still not involved in
care upon discharge (Lefebvre et al., 2008). Additionally, previous research suggests lack
of agreement between family and healthcare providers for care may result in poorer
efforts by patients in therapy and therefore, may result in poorer rehabilitation outcomes
(Sherer et al., 2007). Further, Gouick and Gentleman (2004) suggested that increased
family burden and distress is greatest during this transitional phase. Given the results of
this study and prior research, considering ways to increase family involvement may be
critical in improving outcomes for individuals with TBIs throughout recovery.

Provider interactional skills. In regards to truly listening, all healthcare providers
obtained a majority of ratings between good and very good. Therapists (SLPs, PTs, and
OTs) had slightly higher ratings of good/very good, with approximately 70-80% of ratings falling within this range (mean ratings of ‘good’). Approximately 55% of doctors fell within the good/very good range (mean ratings of ‘fair’) and approximately 58% of nurses fell within the range of good/very good (mean ratings of ‘fair’). This indicates a majority of participants had positive perceptions for providers truly listening to them. However, there still appeared to be a difference across providers for really listening, with therapists receiving higher ratings for really listening than doctors and nursing. Follow-up statistical comparisons are planned, to examine whether these differences were significant. Prior research has identified truly listening as a positive personal provider characteristic (Darragh et al., 2001). The results of this study are consistent in indicating the importance of this characteristic and identify the presence of this key characteristic amongst a vast majority of providers.

For showing care and compassion, therapists (SLPs, PTs, and OTs) again obtained a majority of ratings between good/very good, with approximately 80-85% of ratings falling within this range (mean ratings of ‘good’). Approximately 57% of doctors’ ratings were between good and very good (mean ratings of ‘fair’), indicating a greater percentage of ratings fell between fair (15%) and poor/very poor (27%) in comparison to other provider types. Likewise, approximately 61% of nurses’ ratings were between good and very good (mean ratings of ‘fair’), with 39% of ratings between fair (21%) and poor/very poor (18%). Prior research by Darragh et al. (2001), also identified supportive and respectful providers were better at promoting positive interactions between the patient and provider. These results support the importance of demonstrating genuine care for the patient through showing compassion and respect. These results also add
information related to current provider abilities in showing care and compassion. There appeared to be difference between provider types. Again, therapists were better than doctors and nurses at showing care and compassion. Statistical comparisons are planned to examine whether these differences were significant.

For *being positive*, therapists again obtained higher percentages of ratings of good/very good, with approximately 75-80% falling within this range (mean ratings of ‘good’). Approximately 43% of doctors’ ratings fell between fair (17%) to poor/very poor (27%). Approximately 45% of nurses’ ratings fell between fair (26%) to poor/very poor (19%). There appeared to be a difference across providers, as doctors and nursing had lower percentages falling within this range and a greater percentage falling in the fair to poor/very poor range compared to therapists (mean ratings of ‘fair’). Again, follow-up comparisons will be utilized to evaluate whether these differences were significant.

Darragh et al. (2001), identified frustration by individuals with TBI in interactions with overly negative providers. The results of the current study further support the importance of being positive, adding new information about attitudes by provider-type.

For *acknowledging and validating consequences of TBI*, all providers types received higher percentages of ratings of poor to very poor. Therapists obtained between approximately 26-37% of ratings between fair (10-15%) and poor/very poor (16-22%) with mean ratings in the high-fair range. Approximately 47% of doctor ratings were between fair (13%) and poor/very poor (35%) with means in the low-fair range. Approximately 50% of nurses’ ratings were between fair (18%) and poor/very poor (31%) with mean ratings in the low-fair range. All providers were in the fair range. However, therapists were in the high-fair range and doctors and nurses were in the low-
fair range. Statistical analyses will be conducted to further evaluate this current finding and to determine whether there are significant differences between provider types. However as is identified, all providers may benefit from more explicitly acknowledging consequences of TBI to better support patients. These results are consistent with prior research indicating a lack of information received about the consequences of TBI (Manskow et al., 2018). Not acknowledging the consequences of TBI may also have the potential to lead to increased frustrations during the adjustment to post-TBI life. The results of the current study indicate the need for more to be done to acknowledge and validate the consequences of TBI for all provider types.

For treating symptoms and concerns perceptions were variable across providers. Approximately 70-85% of therapist ratings were good/very good (mean ratings of ‘good’). However, only 55% of doctors’ ratings were good/very good and 45% were between fair (15%) and poor/very poor (30%) with mean ratings of ‘fair’. Similarly, approximately 55% of nurses’ ratings were good/very good and 45% were between fair (22%) and poor/very poor (23%) with mean ratings of ‘fair’. There appeared to be differences between provider types for treating symptoms and concerns. Therapists were better than doctors and nurses at treating symptoms and concerns related to TBI. Statistical comparisons will be completed to determine whether the differences were significant. Prior research indicates doctors may discount effects of TBI or lack the neuroimaging to objectively identify clinical symptoms (Gouick & Gentleman, 2004). The results of the current study indicate certain providers may more directly address and treat symptoms and concerns than other provider types. This may again possibly relate to training and expertise of providers and methods of evaluation to determine a treatment
plan. For example, doctors may rely on neuroimaging, which does not always display the full impairments or symptoms for individuals with TBI. However, more research is necessary to determine if this is the case.

For collaborating directly with the patient for the treatment plan, there were higher percentages of ratings between poor and very poor, especially for doctors and nursing. Approximately 48% of doctors’ ratings were between fair (15%) and poor/very poor (33%) with mean ratings of ‘fair’. Similarly, for nursing, approximately 47% of ratings were between fair (24%) and poor/very poor (24%) with mean ratings of ‘fair’. There appeared to be differences between providers for collaborating with the patient in the treatment plan. Follow-up comparisons are planned, to examine whether the differences were significant. While therapists had higher ratings of good/very good than doctors and nursing, therapists also had higher percentages of ratings between fair (15-17%) and poor/very poor (10-16%) in comparison to other mCARE-TBI responses, with approximately 25-33% of ratings falling within this range (mean ratings of ‘good’). Prior research indicated individuals more involved in their treatment planning process felt more in control of treatment and that the practitioner-client relationship had the greatest impact on treatment perceptions (Darragh et al., 2001). Therefore, collaboration has been identified as a critical element in supporting individuals with TBIs. These results indicate while collaboration skills may vary across providers, all providers may improve on collaborating with the patient directly. Positive and negative perceptions of provider interactional skills were also identified in qualitative analyses.
Qualitative survey findings.

Qualitative analyses revealed positive and negative perceptions across acute, transitional, and chronic phases of recovery. Three main positive perceptions, including interactional skills of providers, specific supports provided, and effective collaboration. Participants specifically emphasized the importance of positive relationships with providers who genuinely cared as important to their care. The way providers interacted with the patient were critical in influencing perceptions of care, which aligns closely with prior research identifying practitioner-client relationships and personal characteristics greatly impacting perception of treatment (Darragh et al., 2001). In the current study, the specific level of provider skill and knowledge of TBI was also identified as crucial to providing specialized interventions, education, and referrals. In the transitional phase, this combination of relationship and perceived skill/knowledge was crucial to developing a sense of trust or therapeutic alliance. This aligns with previous research indicating therapeutic alliance positively impacted rehabilitation outcomes, increased awareness, and decreased depressive symptoms (Schönberger et al., 2006a; Schönberger et al., 2006b). As is outlined by this prior research and the current study, therapeutic alliance may alter efficacy and recovery, further highlighting the importance of considering perceptions of interactions with providers and the care received.

The importance of authenticity, compassion, empathy, and investment in care/collaboration was further emphasized in the chronic phase. Individuals with TBI identified value in collaborating with the rehabilitation team, inclusion of family in the team, and developing an individualized plan of care. The importance of personal characteristics of providers including directly involving the patient in the treatment
planning process was also identified by Darragh et al. (2001) and O’Callaghan et al. (2010). In the transitional and chronic phases, individuals specifically discussed the value of group therapy. Prior research identifies several positives for peer support group participation including increasing knowledge about TBI, increased quality of life, better social communication skills, and increased ability to cope with depression (Hibbard et al., 2002; Keegan, Murdock, Suger, & Togher, 2019). Referrals to mental health professionals was also identified as important to chronic phase recovery. Prior research indicates high correlations between TBI and mental health including depression, anxiety, and post-traumatic stress disorder (Bombardier et al., 2010; Gouick & Gentleman, 2004; Jorge et al., 2004). Therefore, appropriate referrals including those to mental health professionals are critical, especially during the chronic phase of recovery.

Concerns across contexts included negative perceptions of problematic interactions, failure to provide specific supports, and limitations to services. Providers who do not listen, fail to offer opportunities to clarify, and who are disrespectful (condescending) or dismissive are particularly frustrating for individuals with TBI. In transitional and chronic phases, negative provider attributes included being uninterested, arrogant, annoyed, or rushed. It follows that a lack of collaboration, referrals, and necessary services are perceived as detrimental to recovery. During the transitional phase, a lack of clarity in discharge planning such as lack of follow-up or referrals, discharge timing, inadequate education, and a lack of family involvement were identified as particularly problematic. This is consistent with previous research indicating disorganized arrangements, insufficient information, lack of coordination of care, and lack of involvement of family during the transitional phase of recovery (Piccenna et al., 2016;
Sample & Darragh, 1998). Finally, a lack of specialized training, knowledge, and skills are problems across the recovery continuum, but particularly affect access to proper care in transitional and chronic phases of recovery. This is consistent with prior research by Lefebvre et al. (2008) and Dams-O’Connor et al. (2018) identifying a lack of resources provided for long-term follow-up and lack of brain injury specific knowledge resulting in increased frustrations for individuals with TBI.

Part Two: Semi-structured Interviews

Disruptions to psychosocial reintegration following TBI

The five individuals with mild TBI who participated in qualitative interviews also completed the SPRS-2. The perceived effects on work and leisure, relationships, living skills, and overall psychosocial constructs varied across participants. Work and leisure activities changed moderately (mean = 2.1, SD= 1.13) and ranged from a little change to extreme change. Little to no change was perceived in relationships (mean = 2.88, SD= 1.03), with the exception of P5, who reported extreme change. Likewise, little to no change was perceived in living skills post-TBI (mean = 3.35, SD =0.80). Overall, little to moderate change was perceived in psychosocial constructs (mean = 2.78, SD =0.97 ) with P3 and P5 reporting the most substantial change (moderate).

One could argue that self-perceptions of these individuals with TBI may not be accurate. No proxy measures of psychosocial reintegration, such as partner ratings, were included. Further, their perceptions at the time of the interviews may be very different than other points along their recovery continuum, noting that participants were now several years post-TBI. Conversely, these scores represent their perceptions and may be
accurate for individuals with mild TBI in the chronic phase. The perceptions of the
individual with TBI are likely to have the greatest impact on their own attitudes towards
the healthcare system. Prior research indicated self-report measures including subjective
well-being, post-concussion symptoms, pain, and social interaction were possibly
predictive of certain variables such as employment (Sherer et al., 2014). Sherer et al.
(2014), also concluded self-report variables may assist in prediction of participation
outcomes. Essentially, personal attitudes may have the potential to impact functional
outcomes, and therefore, are critical to consider especially in the context of healthcare.
While it was not explored directly, there does not seem to be a direct relationship
between perceived psychosocial outcomes and healthcare perceptions. While P5
identified both poor psychosocial outcomes and negative healthcare perceptions, other
participants such as P3 identified poor perceived psychosocial outcomes but reflected
many positive healthcare experiences and an overall positive experience within the
healthcare setting. For another participant, due to support and opportunities provided
through the TBI community, an increase within the social network was identified on the
SPRS-2 post-injury. This may further highlight the importance of healthcare
professionals providing information about peer support groups and other resources for
TBI survivors to better provide wholistic, person-centered care.

The Phenomenon of living with a mild TBI

The experience of living with a mild TBI is clearly unique to every individual, as
is evident in personal case descriptions. Access to specialized care and ongoing support
appears to be a crucial element influencing the overall tone of the healthcare experience.
This is consistent with prior research identifying the importance of specialized care and
specific knowledge about brain injury (Dams-O’Connor et al., 2018; O’Callaghan et al., 2010). Although all individuals encountered challenges and frustrations, overall tone was clearly more critical for individuals who perceived a greater preponderance of less effective care and support. An overall sense of the phenomenon of living with a mild TBI arose out of common themes reported across participants.

_Frustrating and exasperating_. Individuals with mild TBI described it as a frustrating and exasperating experience. This perception arises out of a sense that doctors (and potentially other providers) are not listening to them, dismissed or minimized their concerns, and left them feeling disenfranchised. These perceptions of feeling discounted and marginalized are consistent with prior research (Gouick & Gentleman, 2004; Sample & Darragh, 1998). Further, the experience decimated their lives, altering their ability to engage in life activities that matter to them most, including social and employment changes. These specific concerns are somewhat at odds with what they reported in the SPRS-2, suggesting that overall impressions of psychosocial reintegration may not always take into account specific losses, like not being able to tolerate going to one’s favorite sporting events due to noise and overwhelming stimuli or the shear pain they endured/continue to endure. Part of this overarching frustration and exasperation related to their need to self-advocate and navigate the process, rather than being directly referred to necessary services and resources. Overall, the results within this study are consistent with prior research (Gouick & Gentleman, 2004; Khan et al., 2003; Sample & Darragh, 1998) and add specific information related to the overall experience across the continuum of recovery.
Referrals, availability, and following up with providers. Access to necessary care was identified as a challenge across participants. Specific barriers to access included lack of referrals, lack of availability of providers and lack of follow-up from providers. Many participants identified specific frustrations in attempting to obtain necessary services. Overall, participants who did not obtain necessary referrals and specific information during the transitional phase, continued to struggle throughout the chronic phase to obtain services and adjust to post-TBI life. Lefebvre et al. (2008) identified a shortage of post-rehabilitation resources resulting in individuals needing to independently find resources and indicated this may have resulted in increased long-term difficulties. This was consistent with findings in this study indicating that many participants felt the need to independently navigate and advocate for services during the chronic phase of recovery. The need to self-advocate and independently navigate the healthcare system led to increased frustrations for many during the chronic phase. Others identified frustration with lack of availability of providers and follow-up services during the chronic phase. O’Callaghan et al. (2010) also identified increased lack of services and lack of follow-up during later phases of recovery, especially during the transitional and chronic phases. The current study adds additional evidence supporting the need for follow-up services in the chronic phase. It is important to note, those who received good transitional support and appropriate follow-up had more positive perceptions of the chronic phase support.

Prior research about the chronic phase of recovery primarily focused on individuals with moderate and severe TBI (Andelic et al., 2014; O’Callaghan et al., 2010). The current study identifies the additional and unique challenges individuals with mild TBIs may face in accessing healthcare. Some of the interview participants did not
receive formal acute care, and instead obtained services through urgent care or office-based visits. For some participants, this resulted in increased frustrations due to misdiagnosis or lack of receiving a clear diagnosis as has also been identified in prior research (Duff et al., 2002; Sample & Darragh, 1998).

*Types of provider interactional styles.* While all participants identified examples of providers with effective interactional styles, all of them also identified negative interactional styles, including being dismissive or disregarding their symptoms. This finding reiterates a common frustration identified within the survey investigation, present within mCARE-TBI questionnaire findings and qualitative comments. For many of the participants, their symptoms were directly dismissed. This included specific frustrations related to discounting and minimizing patient-reported symptoms. Many providers insisted on evaluating physical and observable symptoms, while disregarding the patient’s thoughts on treatment entirely and refusing to collaborate with the patient. For one of the participants, the negative experience with one provider resulted in apprehension with other providers with whom she later had positive experiences. This indicates prior healthcare perceptions may impact future healthcare experiences. While participants reflected on negative interactional styles exhibited by providers, positive interactional styles and attributes were also identified.

Positive experiences included validating and acknowledging symptoms and providing individualized care. Therefore, while dismissing and discounting symptoms was damaging to the relationship, validating and acknowledging symptoms allowed for therapeutic alliance and trust to be built. Overall, these results are consistent with previous research identifying individuals with mild TBI may feel marginalized and
discounted by physicians (Gouick & Gentleman, 2004; Sample & Darragh, 1998). Additionally, the practitioner-client relationship has a great impact on perceptions of treatment and poor practitioner-client relationships may result in perceptions of services as incomplete, ineffective, and possibly detrimental to the recovery process (Darragh et al., 2011). Therapeutic alliance is critical in supporting rehabilitation outcomes. Prior research indicates therapeutic alliance, specifically the emotional bond with the provider, was predictive of awareness level and reducing depressive symptoms (Schönberger et al., 2006a; Schönberger et al., 2006b). Results from this study specifically indicate that for individuals with mild TBI, providers with a willingness to try are often most valued, especially in comparison to providers dismissing and discounting the reality that the individual with the TBI must face every day.

Information received about brain injury and what to expect. Many participants identified receiving minimal to no resources on what to expect or what to do following their mild TBI. This resulted in individuals feeling alone in the recovery process and needing to self-seek resources for support. One participant felt that the overall lack of resources provided ended up being detrimental to her overall recovery process. This triangulates well with survey findings and is consistent with prior research indicating the lack of resources received may have resulted in increased long-term difficulties (Jourdan et al., 2017; Lefebvre et al., 2008). In addition to not being provided with specific information about TBI, participants also identified frustrations related to being provided a false timeline for recovery. Several participants stated providers would give them a certain time span for a specific amount of recovery to occur. When there were deviations from this timeline or minimal progress was made, individuals felt discouraged and
frustrated. The lack of specific and accurate information resulted increased frustrations, which has also been identified in prior research (Lefebvre et al., 2008). The results of the current study provide additional information about the extent of the impact on a lack of resources and education on recovery, especially in the chronic phase. Lack of information and education resulted in increased frustration and stress through needing to independently figure out how to adjust to post-TBI life.

Recovery continuum. The results of the current study provide specific information related to care across acute, transitional, and chronic phases of recovery. Overall, the results align closely with those identified previously by O’Callaghan et al. (2010) investigating perceptions across phases by individuals with moderate to severe TBIs in Australia. However, the current study adds specific information related to perceptions of individuals with mild TBI across the recovery continuum, which has not previously been directly investigated.

As it relates to the acute phase of recovery, the results of the current study are consistent with findings by Manskow et al. (2018) indicating fairly high overall satisfaction within the acute care setting. In the current study, participants reflected on consistently receiving specialized care and necessary services during the acute phase of recovery. Direct access to specialists such as neurologists resulted in patients feeling better supported and the symptoms that were experienced during the acute phase were directly addressed. This resulted in generally positive experiences and a more positive perception of the acute phase and was consistent with findings by O’Callaghan et al. (2010).
In regard to the transitional phase, several of the interview participants indicated receiving a lack of information about consequences of TBI and what to expect which also aligns with findings by Piccenna et al. (2006). When specific information and clear explanations were provided, participants valued the information, but when it was not provided this led to increased feelings of frustration. Overall, the transitional phase in recovery was a pivotal period for determining perceptions of support extending into the chronic phase of recovery. Participants receiving appropriate referrals and specific information felt better supported in both the transitional and chronic phase of recovery. However, participants not obtaining necessary referrals and specific information during the transitional phase, continued to struggle throughout the chronic phase to obtain services and adjust to post-TBI life. Lefebvre et al. (2008) identified a shortage of post-rehabilitation resources resulting in individuals needing to independently find resources. This was consistent with findings in this study indicating that many participants felt the need to independently navigate and advocate for services during the chronic phase of recovery. The need to self-advocate and independently navigate the healthcare system led to increased frustrations for many during the chronic phase. Others identified frustration with lack of availability of providers and follow-up services during this phase. Those who received good transitional support and appropriate follow-up generally had more positive perceptions of the chronic phase support. However, those who experienced a lack of coordination of care and information about TBI, continued to struggle throughout the chronic phase of recovery. This is consistent with previous research by Lefebvre et al. (2008) suggesting that a lack of resources given to family caregivers may have resulted in more long-term difficulties. Overall, the results of the current study indicate a need for
more support during the transitional and chronic phases of recovery to better support outcomes for individuals with TBI. There are many continued needs in the chronic phase of recovery and several that currently are being unmet, which is also consistent with prior research (Andelic et al., 2014; Jourdan et al., 2017). The information from this study also specifically outlines critical factors influencing the chronic phase and additional areas of need for individuals with TBIs.

**Clinical Implications.**

Individuals with TBI identify both positive and negative perceptions of their healthcare experiences, which may help healthcare providers to better meet the needs of individuals with TBI in the future. The interactional skills of providers were identified as crucial to effective care. Training specific communication and interactional skills to providers is an important step towards better service delivery. Specific knowledge of TBI and specialized services/interventions are critical for supporting individuals with TBI. In the present investigation, those participants who had more access to specialized care reported more positive perceptions of healthcare provision across all phases of the recovery continuum. More specialized knowledge may also decrease incidence of dismissing symptoms or discounting an individual with TBI’s thoughts on treatment. All providers may also provide better care by directly collaborating with the patient in treatment planning. Promoting service access through referrals, clear discharge planning and communication, information about resources and services such as community programs and support groups, and coordinated care were all identified as important steps by individuals with TBI. A lack of clear instruction regarding the discharge plan was identified as problematic across all providers. Further, failure to involve family members
in care and discharge planning was noted across all providers. Each of these issues are particularly pertinent in the transitional to chronic phases of recovery.

While not the primary focus of the current investigation, it may be necessary to consider other factors impacting healthcare perceptions that may not directly be related to the healthcare experience, particularly in the chronic phase. After sustaining a TBI, individuals undergo many life changes. For many, employment status frequently changes as the result of TBI and often consists of obtaining a job with a lower status/fewer demands or not being able to return to work due to TBI-related deficits as has been identified in the current study and in previous research (Stambrook et al., 1990; van Velzen et al., 2009). In the present investigation, there was a significant difference in pre-and post-TBI employment among survey respondents. In the United States healthcare system, employer-based insurance is the most common insurance type, with nearly 55.1% of Americans using this form of insurance in 2018 (Berchick, Barnett, & Upton, 2019). Therefore, employment status change may also result in insurance status change as it relates to context of healthcare perceptions and specifically healthcare access in the United States. In fact, the results of the survey indicated across all phases of recovery (acute, transitional, and chronic), expenses associated with services and insurance issues were identified as a limitation to services and contributed to negative healthcare experiences.

In order to effectively meet the needs of individuals with TBI across phases of recovery, it is critical to treat the whole person. Additionally, it is necessary to consider the consequences of TBI including physical, cognitive, psychosocial, and economic consequences. Ongoing support is necessary, especially in the chronic phase of recovery.
In order to improve support in the chronic phase, providing comprehensive, individualized, and coordinated care is necessary in the transitional phase. Information about ongoing and long-term supports should be provided early on in the recovery phase to improve perceptions of support throughout recovery, including the chronic phase.

**Limitations.**

Limitations of the current study include a relatively small sample size for the survey portion of the investigation. While attempts were made to recruit a large sample size, time constraints and feasibility resulted in a decreased ability for multiple contacts to be made to potential participants. This may have resulted in decreased response rate. Additionally, due to the sampling method as well as a relatively small sample size, the current sample is not entirely representative of TBI population demographics, and thus, there is limited generalizability of results. Of the 69 million TBIs sustained each year, approximately 81% are classified as mild, 11% as moderate, and 8% as severe (Dewan et al., 2018). In the current study, only approximately 26% sustained a mild TBI, 17% sustained a moderate TBI and, approximately 47% sustained a severe TBI. Additionally, majority of the individuals participating in the current study were Caucasian with higher levels of education, which is not fully representative of all individuals sustaining TBIs each year. The current study used a non-random convenience sample in order to recruit individuals that self-identified as having a TBI. As a result, there are limitations to the overall generalizability of results.

While the sample size of the survey was also relatively small, the number of respondents willing to complete the follow-up interview was quite large. The present investigation only analyzed five of the interviews, including individuals with mild TBI.
However, we are in the process of completing the remaining 35 interviews with relatively balanced representation across severity levels. As those findings are analyzed, we are poised to make a substantive contribution to the understanding of the phenomenon of healthcare perceptions related to living in the chronic phase of recovery. Future research studies should include a larger sample size of individuals with TBI. The present investigation reached over 800 support groups and 11 online/social media based support networks, which is a substantial recruitment effort. The fact that we only recruited 84 participants (64 that met inclusion/exclusion criteria) likely relates to the rigor of our recruitment process. More individualized recruitment methods and repetition of recruitment calls in the future may result in better recruitment. Future research may also investigate potential differences in perceptions by severity level (e.g. mild, moderate and severe). Our ongoing efforts to interview and analyze phenomenological experiences of individuals with TBI across the severity continuum may address this void and allow more stratified implications about perceptions and experiences across that continuum.
REFERENCES:


## The CARE Measure

1. Please rate the following statements about today's consultation. Please tick the box for each statement and answer every statement.

<table>
<thead>
<tr>
<th>How was the doctor at ...</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Making you feel at ease.... (being friendly and warm towards you, treating you with respect; not cold or abrupt)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>2. Letting you tell your &quot;story&quot; .... (giving you time to fully describe your illness in your own words; not interrupting or diverting you)</td>
<td>☐</td>
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<td>☐</td>
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<td>☐</td>
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<tr>
<td>3. Really listening .... (paying close attention to what you were saying; not looking at the notes or computer as you were talking)</td>
<td>☐</td>
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<tr>
<td>4. Being interested in you as a whole person .... (asking knowing relevant details about your life, your situation; not treating you as &quot;just a number&quot;)</td>
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<td>☐</td>
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<tr>
<td>5. Fully understanding your concerns ..... (communicating that he/she had accurately understood your concerns; not overlooking or dismissing anything)</td>
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<tr>
<td>6. Showing care and compassion.... (seeming genuinely concerned, connecting with you on a human level; not being indifferent or &quot;detached&quot;)</td>
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<td>7. Being Positive .... (having a positive approach and a positive attitude; being honest but not negative about your problems)</td>
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<tr>
<td>8. Explaining things clearly .... (fully answering your questions, explaining clearly; giving you adequate information; not being vogue)</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>9. Helping you to take control .... (exploring with you what you can do to improve your health yourself; encouraging rather than &quot;lecturing&quot; you)</td>
<td>☐</td>
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<tr>
<td>10. Making a plan of action with you .... (discussing the options, involving you in decisions as much as you want to be involved; not ignoring your views)</td>
<td>☐</td>
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Appendix B: TBI Perceptions Survey and Modified CARE Questionnaire for TBI

TBI Perceptions Survey

Introduction: Thank you for taking the time to complete this survey. We are interested in the perceptions of care YOU received following YOUR traumatic brain injury (TBI) because this may help improve the types of services provided for others in the future. The questions that follow will address your perceptions.

Note there are audio files for each question that will look like the file above. You may press play on each question to hear it read out loud, if you are interested in this option.

Q1 Overall, how were healthcare providers at delivering QUALITY CARE IN THE FOLLOWING SETTINGS...

<table>
<thead>
<tr>
<th></th>
<th>Very Poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Does Not Apply</th>
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</thead>
<tbody>
<tr>
<td>Acute care (hospital)</td>
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<td>Rehab</td>
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<tr>
<td>Long-term care</td>
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</table>

Please respond to the following questions based on what you recall from acute care or what others have told you about the experience in acute care with healthcare providers.

Because rating each type of provider does not allow you to rate specific providers that were either particularly good or bad, we invite you to comment on this in the follow-up questions. Note this may include different types of doctors, multiple nurses, or therapists.
These follow-up questions are OPTIONAL.

Q2 How were healthcare providers at MEETING YOUR OVERALL NEEDS in the acute care setting?

<table>
<thead>
<tr>
<th>Professionals</th>
<th>Very Poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
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<td>Occupational therapy</td>
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<td>Physical therapy</td>
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<tr>
<td>Speech-language therapy</td>
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<tr>
<td>Nursing</td>
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<td>Other: ____</td>
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Q2A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________

Q2B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:
Q3 How were healthcare providers at assisting with the TRANSITION HOME following discharge from the hospital after your TBI... (supports provided to facilitate the transition, resources and information provided, information for community-based groups provided)

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<thead>
<tr>
<th></th>
<th>Very Poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
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<tr>
<td>Occupational therapy</td>
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<td>Physical therapy</td>
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<td>Speech-language therapy</td>
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<tr>
<td>Nursing</td>
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<td>Other: _____</td>
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Q3A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

Q3B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:
For the next set of questions, consider your overall experience when leaving the hospital and returning home:

Again, because rating each type of provider does not allow you to rate specific providers that were either particularly good or bad, we invite you to comment on this in the follow-up questions. Note this may include different types of doctors, multiple nurses, or therapists.

These follow-up questions are OPTIONAL.

Q4 How were healthcare providers at EXPLAINING THINGS CLEARLY UPON DISCHARGE... (helping you know what to expect when leaving the hospital, providing information about your brain injury, providing information for who to follow-up with and when)
Q4A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________

Q4B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________
Q5 How were healthcare providers at INVOLVING YOUR FAMILY MEMBERS/CARE PARTNERS IN YOUR CARE UPON DISCHARGE...(receiving information, supporting their ability to assist with care following hospital discharge)

<table>
<thead>
<tr>
<th>Professional</th>
<th>Very Poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
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<tr>
<td>Occupational therapy</td>
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<td>Physical therapy</td>
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<tr>
<td>Speech-language therapy</td>
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<tr>
<td>Nursing</td>
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<tr>
<td>Other: _____</td>
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</table>

Q5A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:
Q5B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________

Page Break

Please tell us some things about yourself. This series of questions are to find out about demographic information.

Q6 How did you find out about this survey?

- Facebook group
- From group leader in community-based/face-to-face group
- Other ____________________________________________

Q7 What is your date of birth? Please use the following format in your response: MM/DD/YYYY

________________________________________________________________

Q8 When did your traumatic brain injury occur? Please use the following format in your response: MM/DD/YYYY

________________________________________________________________
Q9 What is your gender?

- [ ] Male
- [ ] Female
- [ ] Other: ________________________________________________
- [ ] Prefer not to answer

Q10 Are you of Hispanic, Latino, or of Spanish origin?

- [ ] Yes
- [ ] No
- [ ] Prefer not to answer
Q11 How would you describe yourself? (You may check all that apply)

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Other: ________________________________________________
☐ Prefer not to answer

Q12 What state do you currently live in?
________________________________________________________________

Q13 What was your primary type of medical insurance at the time of your injury?

☐ Medicare
☐ Medicaid
☐ Private insurance
☐ Other: ________________________________________________
☐ No health insurance at time of injury
Q14 What was the highest level of education you received?

<table>
<thead>
<tr>
<th>Less than high school</th>
<th>high school</th>
<th>2 year college</th>
<th>4 year college</th>
<th>advanced degree</th>
</tr>
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Page Break

Q15 Which of the following best describes your employment status PRIOR TO INJURY?

- o Employed, working 1-39 hours per week
- o Employed, working 40 hours or more per week
- o Not employed, looking for work
- o Not employed, not looking for work
- o Retired
- o Unable to work due to disability
Q16 Which of the following best describes your CURRENT employment status?

- Employed, working 1-39 hours per week
- Employed, working 40 hours or more per week
- Not employed, looking for work
- Not employed, not looking for work
- Retired
- Unable to work due to disability caused by TBI
- Unable to work due to pre-existing disability

Q17 What was the severity of your TBI?

<table>
<thead>
<tr>
<th>Concussion/mild TBI</th>
<th>moderate TBI</th>
<th>severe TBI</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>o</td>
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</tr>
</tbody>
</table>

Q18 What was your Glasgow Coma Scale or GCS score at time of admission to the hospital? Please select the range that includes your GCS score.
Q19 What was the cause of your traumatic brain injury?

- Motor vehicle accident (MVA)
- Fall
- Sports
- Domestic violence/assault
- Other: ________________________________

Q20 Have you ever been diagnosed with or told you have aphasia?

- Yes
- No
- Unsure

Page Break
Please respond to the following statements about your TBI:

Q21 How long were you unconscious?

- 0-30 minutes
- 30 minutes- 24 hours
- Greater than 24 hours

Q22 How long were you in a coma?

- Less than a day
- 1-2 weeks
- More than 3 weeks
- More than a year
- I was not in a coma
Q23 Did you experience post traumatic amnesia? (difficulty identifying person, place and time; and having trouble holding on to new memories)

- Yes
- No
- Unsure

Q23A How long did your post traumatic amnesia last?

- Less than 5 minutes
- 5-59 minutes
- 1-24 hours
- 1-7 days
- More than 7 days

Q24 How long were you hospitalized? Please select the response that is closest to your length of initial hospital stay following injury.

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<th>1 day or less</th>
<th>2-3 days</th>
<th>4-5 days</th>
<th>6-7 days</th>
<th>8 days or more</th>
<th>I was not hospitalized or N/A</th>
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Q25 I stayed in the following places after my brain injury (Please check all that apply):

- rehabilitation facility
- acute care hospital
- trauma center
- outpatient hospital
- transitional care facility
- long term acute care
- other
- N/A

Q26 I received follow-up care at the following times after my brain injury (Please check all that apply and that are closest to the points in time you received follow-up):

- Initial only, no follow-up
- 1 week
- 1 month
- 6 months
- 1 year
- More than 1 year
- N/A

Q27 Did you receive occupational therapy?

- Yes
- No
- Unsure

*Skip To: Q27A If Did you receive occupational therapy? = Yes
Skip To: Q28 If Did you receive occupational therapy? = No
Skip To: Q28 If Did you receive occupational therapy? = Unsure*
Q27A How many weeks did you receive occupational therapy? Please use the slider to indicate approximately how many weeks you received occupational therapy.

Q28 Did you receive physical therapy?

- Yes
- No
- Unsure

Q28A How many weeks did you receive physical therapy? Please use the slider to indicate approximately how many weeks you received physical therapy.
Q29 Did you receive speech-language therapy?

- Yes
- No
- Unsure

Skip To: Q29A If Did you receive speech-language therapy? = Yes
Skip To: Q30 If Did you receive speech-language therapy? = No
Skip To: Q30 If Did you receive speech-language therapy? = Unsure

Q29A How many weeks did you receive speech-language therapy? Please use the slider to indicate approximately how many weeks you received speech-language therapy.

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Q30 Did you receive an additional type of service following your traumatic brain injury? If you select yes, please use the entry space to specify the types of other services.

- Yes
- No
- Unsure

Skip To: Q30A If Did you receive an additional type of service following your traumatic brain injury? If you sele... = Yes
Skip To: Q If Did you receive an additional type of service following your traumatic brain injury? If you sele... = No
Q30A How long did you receive this other type of service?

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Page Break

For the next set of questions, consider your collective experience with healthcare providers for addressing long-term effects of your TBI.

While you may have encountered multiple healthcare providers over that time, consider your overall impressions when responding.

Again, because rating each type of provider does not allow you to rate specific providers that were either particularly good or bad, we invite you to comment on this in the follow-up questions. Note this may include different types of doctors, multiple nurses, or therapists.

These follow-up questions are OPTIONAL.

Q31 How were healthcare providers at really LISTENING... (giving you time to fully describe your concerns in your own words)
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Q31A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________

________________________________________________________________

Q31B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which providers and the nature of the experiences:

________________________________________________________________

________________________________________________________________
Q32 How were healthcare providers at showing CARE AND COMPASSION (seemingly genuinely concerned, treating you as a competent individual)

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Q32A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________

Q32B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________
Q33 How were healthcare providers at BEING POSITIVE... (having a positive approach and a positive attitude)

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Q33A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________

Q33B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals the nature of the experiences:

________________________________________________________________
Q34 How were healthcare providers at formally ACKNOWLEDGING THE CONSEQUENCES of your TBI... (validating symptoms reported, discussing severity clearly)

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Q34A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________________________________

________________________________________________________________________________________
Q34B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________

Q35 How were healthcare providers at TREATING SYMPTOMS AND CONCERNS related to traumatic brain injury... (providing information, treating symptoms, providing contact information to schedule appointments)

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Q35A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

________________________________________________________________
Q35B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

__________________________________________________________________

Q36 How were healthcare providers at COLLABORATING WITH YOU in your treatment plan... (having an active role in treatment plan, addressing personal values and goals, individualizing plan for treatment)

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Q36A If you had particularly GOOD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

____________________________________________________________________________________

Q36B If you had particularly BAD interactions with specific providers (doctors, therapists, nurses), please indicate which professionals and the nature of the experiences:

____________________________________________________________________________________

Page Break

Q37 If you would be interested in participating in a follow-up interview, please provide contact information including your phone number and email address. Please state whether your email or your phone is your preferred method of contact.

____________________________________________________________________________________

Thank you for completing this survey. We appreciate your time and participation.

If you have experienced a negative emotional reaction as a result of your participation in this survey or have any questions or concerns, you may contact Dr. Jerry Hoepner (email: hoepnejk@uwec.edu; phone: (715) 836-3980), who is overseeing this project. You may also consider contacting your healthcare provider.

End of Block: Default Question Block

167
Appendix C: Email Correspondence; Survey Cover and Consent Letter

Dear brain injury group leader,

My name is Katie Spreitzer and I am a speech-language pathology Master’s student at the University of Wisconsin- Eau Claire. I am currently conducting my thesis project entitled, “Perceptions of post-TBI experiences by individuals with traumatic brain injury”. This project aims to identify current perceptions of individuals with TBI as it relates to long-term care. Results obtained from this study may have the potential to improve service-delivery and will provide greater insight into chronic care for TBI.

I am reaching out to you wondering if you would be interested and willing to share a link to an online-based Qualtrics survey to your group members who have experienced a traumatic brain injury. If the individual has an acquired brain injury due to another cause such as stroke, tumor, or other etiologies, they would not qualify for this specific survey. If interested the members in your group with TBI could share their experiences as it relates to healthcare experiences through the online survey. The survey includes some demographic questions, some questions related to acute care, the transition to home, and many questions about long-term care. Group members confidentiality will be maintained and this survey will not involve any personal identification. While reflecting on healthcare experiences may evoke positive or negative feelings associated with those experiences, no other substantial risks are anticipated. Participants will be provided with contact information for Dr. Jerry Hoepner, (email: hoepnejk@uwec.edu; phone: (715) 836-3980) who is overseeing this project. Participants will also be encouraged to consider contacting their healthcare provider if a negative emotional reaction occurs.

This study has been approved by the University of Wisconsin-Eau Claire Institutional Review Board.

If you have any questions for me or would like any additional information, please let me know.

If interested, please provide your group members with the Cover Letter attached in this email.

Individuals interested in participation may then follow this link to the Qualtrics survey: https://uweauclaire.qualtrics.com/jfe/form/SV_9vITMG7WFnrtR3
Also, if you are interested in sharing the survey with your group, please respond to this email. This way we will be able to continue to correspond as needed. The survey will be open until November, 30th.

Thank you for your consideration,
Katie Spreitzer

2019-2020

Dear Prospective Research Participant:

You are invited to participate in the study “Perceptions of post-TBI healthcare experiences by individuals with traumatic brain injury” conducted by graduate student, Katie Spreitzer, in the Department of Communication Sciences and Disorders at the University of Wisconsin-Eau Claire. This project is being conducted under the supervision of Dr. Jerry Hoepner. The primary purpose of this survey research is to identify the perspectives of individuals with traumatic brain injury (TBI) as it relates to healthcare and the long-term management of TBI. This survey will be beneficial to healthcare professionals by providing valuable information about current perspectives and may provide potential ways to improve service-delivery practices for individuals with TBI. The survey asks a series of questions related to background. The survey then asks for you to broadly reflect on your experiences with healthcare through the use of rating scales and optional open-ended questions. The final question on the survey allows you provide your contact information, if you would be interested in participating in an interview. The survey will take approximately 20 to 30 minutes to complete.

You are seeing this post because you are a participant of a community. Below is a link to the Qualtrics survey. By clicking on the anonymous link to the survey, you are giving your informed consent to participate.

Qualtrics link: https://uweauclaire.qualtrics.com/jfe/form/SV_9vlITMG7WFnrtR3

You must:

- Be at least 18 years old currently and at the time of onset of your TBI
- Self-report as having a traumatic brain injury
- Not be currently under guardianship
- Be at least one year post-onset
- Have no other neurological deficits unrelated to or prior to the TBI (e.g. stroke, dementia, Parkinson’s disease, and other neurological diseases),
- No diagnosed psychiatric disorders prior to TBI (e.g. schizophrenia, obsessive compulsive disorders)
No identifying information is required and your participation will remain anonymous, unless you choose to leave your contact information for an interview. Any identifying information provided will be removed from all publications, presentations, and the thesis document.

Benefits of participation in this survey include improving knowledge in the area of speech-language pathology as it relates to healthcare. Additional benefits include helping develop future research and the potential to improve future service-delivery practices. While reflecting on healthcare experiences may evoke feelings associated with those experiences, no other substantial risks are anticipated. While this risk is anticipated to be minimal, If you experience a negative emotional reaction, you may contact Dr. Jerry Hoepner (email: hoepnejk@uwec.edu; phone: (715) 836-3980), who is overseeing this project, to address those concerns. You may also consider contacting your healthcare provider. Participation is completely voluntary and you may withdraw from the survey at any time. The survey will close on November, 30th.

Participation in the Qualtrics survey will involve answering several multiple choice questions, open-ended questions, and using rating scales to identify demographic variables and perspectives related to healthcare. Note that there are audio recordings provided after each question that you may utilize, if you would like.

I understand that if I have any questions concerning the purpose or procedures associated with this research project, I may call or write:

Katie Spreitzer  
(630) 306-8583  spreitka@uwec.edu

Dr. Jerry Hoepner  
(715) 836-3980  hoepnejk@uwec.edu

I understand that if I have questions or concerns about the treatment of human subjects in this study, I may call or write:

Dr. Michael Axelrod, Chair  
Institutional Review Board for Protection of Human Subjects  
Schofield 17  
University of Wisconsin-Eau Claire  
Eau Claire, WI 54702-4004  
Telephone: 715-836-2373

Thank you for your time and consideration.

Katie Spreitzer, B.S.
spreitka@uwec.edu

Dr. Jerry Hoepner, Ph.D., CCC-SLP
hoepnejk@uwec.edu
Appendix D: Interview Consent and Cover Letter

Interview Consent

2019-2020

Dear Prospective Research Participant:

You are invited to participate in the study “Perceptions of post-TBI healthcare experiences by individuals with traumatic brain injury” conducted by graduate student, Katie Spreitzer, in the Department of Communication Sciences and Disorders at the University of Wisconsin-Eau Claire. This project is being conducted under the supervision of Dr. Jerry Hoepner. The primary purpose of this research is to identify the perspectives of individuals with traumatic brain injury (TBI) as it relates to healthcare and the long-term management of TBI. This interview will be beneficial to healthcare professionals by providing valuable information about current perspectives and may provide potential ways to improve service-delivery practices for individuals with TBI.

Participating in this study would include:
· Completion of a questionnaire about pre-injury and post-injury life.
  o This should take approximately 10-15 minutes to complete.
· Completion of an interview involving three main questions with scripted follow-up questions regarding your perspectives of healthcare, specifically as it relates to the long-term management of your TBI.
  o The interview should take approximately 20-25 minutes to complete.
  o This is a total of approximately 30-40 minutes.
· The interviews will be conducted via BlueJeans, a video conferencing application, in which the audio and video is encrypted and will be stored on a secure server.

Below is a question for you to provide your informed consent to participating in the questionnaire and interview. You must be at least 18 years old, self-report as having a traumatic brain injury, and are not under guardianship. You must have been at least 18 years old at the time of onset of your TBI, be at least one year post-onset, no other neurological deficits unrelated to or prior to the TBI (e.g. stroke, dementia, Parkinson’s disease, and other neurological diseases), or diagnosed psychiatric disorders prior to TBI (e.g. schizophrenia, obsessive compulsive disorders).
Benefits of participation in this interview include improving knowledge in the area of speech-language pathology as it relates to healthcare. Additional benefits include helping develop future research and the potential to improve future service-delivery practices. While reflecting on healthcare experiences may evoke feelings associated with those experiences, no other substantial risks are anticipated. While this risk is anticipated to be minimal, if you experience a negative emotional reaction, you may contact Dr. Jerry Hoepner (email: hoepnejk@uwec.edu; phone: (715) 836-3980), who is overseeing this project, to address those concerns. You may also consider contacting your healthcare provider.

Participation is completely voluntary and you may withdraw from the study at any time.

The information you provide will remain confidential. Any identifying information provided will be removed from all publications, presentations, and the thesis document.

I understand that if I have any questions concerning the purpose or procedures associated with this research project, I may call or write:

Katie Spreitzer  
(630) 306-8583  
spreitka@uwec.edu

Dr. Jerry Hoepner  
(715) 836-3980  
hoepnejk@uwec.edu

I understand that if I have questions or concerns about the treatment of human subjects in this study, I may call or write:

Dr. Michael Axelrod, Chair  
Institutional Review Board for Protection of Human Subjects  
Schofield 17  
University of Wisconsin-Eau Claire  
Eau Claire, WI 54702-4004  
Telephone: 715-836-2373

- I consent, begin the study
- I do not consent, I do not wish to participate
End of Block: Informed Consent

Electronic Signature (please type your name)
Appendix E: Sydney Psychosocial Reintegration Scale-2 (SPRS-2)

SYDNEY PSYCHOSOCIAL REINTEGRATION SCALE – 2 (SPRS-2)
FORM A (SELF)
ROBYN L TATE
DEVELOPED IN ASSOCIATION WITH
ADELINE HODGKINSON, AHAMED VEERABANGSA, ANNE PIAF AND GRAHAME SIMPSON
BRAIN INJURY REHABILITATION UNIT AT LIVERPOOL HOSPITAL, SYDNEY

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<thead>
<tr>
<th>Name:</th>
<th>Sex: _ / _</th>
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<tr>
<td>Date:</td>
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<td>Date of injury:</td>
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Cause of injury: | Duration of coma: | Duration of PTA: |

BACKGROUND INTERVIEW

1. What is your current occupation?
2. What are your work duties at present?
3. What was your job at the time of the injury?
4. What were your work duties in that job?
5. How many jobs have you had since the injury (not including work trials or voluntary work)?
6. What are/were your leisure interests, recreation, hobbies, and club membership, at present and at time of injury?
   6. AT TIME OF INJURY
   7. PRESENT

8. What is/was your weekly program of work, leisure/recreational activities at present and at time of injury?
   8. AT TIME OF INJURY
   9. PRESENT

10. What was your marital status at time of injury?
11. What is it at present?
12. Who was in your circle of close friends at time of injury?
13. Who is in your circle of close friends at present?
14. Who did you live with at time of injury?
15. Who do you live with at present?
### WORK AND LEISURE

#### 1. Current work: Have your hours of work (or study), or the type of work (study) changed because of the injury?
(If you are a student, answer the question in this section in terms of changes in your studies)

- **Not at all:** Same or better.  
  - 4
- **A little:** Now work less hours per week, or work duties (study) have changed for easier/fighter one.  
  - 3
- **Moderately:** Work casualty, or have some help from others in doing some work (study).  
  - 2
- **A lot:** Now unemployed, or in rehabilitation, or in a supported work program, or doing volunteer work, or receive readjustment assistance in studies.  
  - 1
- **Extreme:** Am almost unable to work (study) or is unable to at present.  
  - 0
- **Unable to assess:** Did not work before the injury and still do not work.  
  - NA

#### 2. Work skills: Have the work (study) skills changed because of the injury?

- **Not at all:** Same or better.  
  - 4
- **A little:** Not quite as good, e.g. have to put in a lot of effort to get the same result, get tired easily, lose concentration.  
  - 3
- **Moderately:** Definitely not as good, e.g. sometimes make mistakes.  
  - 2
- **A lot:** Much worse, e.g. I am slower.  
  - 1
- **Extreme:** Very much worse, e.g. make many mistakes, am very slow, work is of poor quality, need constant supervision and/or reminders at present.  
  - 0

#### 3. Leisure: Has there been any change in the number or type of leisure activities or interests because of the injury?

- **Not at all:** Same or more, and done as often or more.  
  - 4
- **A little:** Have most of the same activities and interests, or have the same activities and interests but do them less often.  
  - 3
- **Moderately:** Definitely less, but may have developed new activities and interests.  
  - 2
- **A lot:** Only have some of the leisure activities and interests and have not developed new ones.  
  - 1
- **Extreme:** Almost none or no leisure activities or interests at present.  
  - 0
- **Unable to assess:** Did not have leisure activities before the injury and still do not have leisure activities.  
  - NA

#### 4. Organising activities: Has there been any change in the way you organise work and leisure activities because of the injury?

- **Not at all:** Same or better.  
  - 4
- **A little:** Need prompts or supports from others.  
  - 3
- **Moderately:** More dependent on other people to organise activities, e.g. others suggest what to do and how to go about it.  
  - 2
- **A lot:** Need other people to do the organising, e.g. making arrangements, providing transport.  
  - 1
- **Extreme:** Almost completely or completely dependent on other people to suggest and organise activities at present.  
  - 0

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### Relationships

5. **Spouse or partner:** Did you have a partner or spouse at the time of the injury? 
   - **a) If yes, has the relationship changed because of the injury? If no, go to part b) below.**
     - Not at all: Same or better. ................................................................. 4
     - A little: Not quite the same, but am still able to get along. ...................... 3
     - Moderately: Definitely not the same ................................................ 2
     - A lot: A lot of changes, but I might have the skills to form a new relationship. 1
     - Extreme: Nature of relationship has changed in a major way (e.g., partner takes on most responsibilities or is the primary caregiver), relationship has broken down and I probably do not have the skills to form a new relationship. ...................... 0

   - **b) If no, how much change is there in your ability to form and maintain such a relationship compared to before?**
     - None at all: Same or better .................................................................. 4
     - A little: Not quite the same ..................................................................... 3
     - Moderate: Definitely not the same .......................................................... 2
     - A lot: A lot of changes in relationships with some family members. ............. 1
     - Extreme: Probably do not have or do not have the skills to form a new relationship. ................................................................. 0

6. **Family:** Have your relationships with other family members changed because of the injury?
   - Not at all: Same or better. ........................................................................ 4
   - A little: Not quite the same ........................................................................ 3
   - Moderately: Definitely not the same .......................................................... 2
   - A lot: A lot of changes in relationships with some family members. ............. 1
   - Extreme: Changed in a major way OR a breakdown of relationships with some family members due to effects of the injury. ................................. 0
   - Unable to assess: Did not have contact with family before the injury. ........ NA

7. **Friends and other people:** Have your relationships with other people (outside family, such as close friends, workmates, neighbours) changed because of the injury?
   - Not at all: Same or better. ........................................................................ 4
   - A little: Not quite the same, but still see some friends weekly or more, make new friends, and get along with workmates and neighbours. .......... 3
   - Moderately: Definitely not the same, but still see some friends once a month or more and can make new friends. ............................................. 2
   - A lot: Only see a few friends (or other people outside family), and do not make new friends easily. ............................................................... 1
   - Extreme: See hardly any friends or see none at all (or other people outside the family). ................................................................. 0

8. **Communication:** Have your communication skills (that is, talking with other people and understanding what others say) changed because of the injury?
   - Not at all: Same or better. ........................................................................ 4
   - A little: Some changes, e.g., ramble and get off the point, talk is sometimes inappropriate, have some trouble finding the words to express myself. .......... 3
   - Moderately: Definite changes, e.g., difficulty thinking of things to say, joining in talks with groups of people, only talk about myself. ................................................................. 2
   - A lot: A lot of changes, e.g., having trouble understanding what people say. ......................................................................................... 1
   - Extreme: Major changes, but can communicate basic needs, OR use aids for communication OR communication is almost impossible. ......................... 0

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### Living Skills

9. **Social Skills:** Have your social skills and behaviour in public changed because of the injury?

- **Not at all:** Same or better. 4
- **A little:** Some changes, e.g., am awkward with other people, do not worry about what other people think or want 3
- **Moderately:** Definite changes, e.g., can act in a silly way, am not as tactful or sensitive to other people’s needs 2
- **A lot:** A lot of changes, e.g., am more dependent on other people, am socially withdrawn. 1
- **Extreme:** Major changes, e.g., have difficulty interacting appropriately with other people, behaviour is unpredictable, have temper outbursts in public, require supervision when with other people 0

10. **Personal habits:** Have your personal habits (e.g., your care in cleanliness, dressing and tidiness) changed because of the injury?

- **Not at all:** Same or better. 4
- **A little:** Do not take as much care as before 3
- **Moderately:** Attend to my hygiene, dress and tidiness, but have definitely changed in this area; need supervision 2
- **A lot:** Need prompts, reminders or advice from others, but respond to these; OR need stand-by assistance 1
- **Extreme:** Need prompts, reminders or advice from others, but respond to these only after repeated requests; need hand-on assistance; OR am totally dependent for assistance 0

11. **Community travel:** Have your use of transport and travel around the community changed due to the injury?

**NOTE:** Do not include the driver of transport, or other passengers using such transport, in rating whether a you can travel “alone” or “by yourself”.

- **Not at all:** Same or better. 4
- **A little:** Unable to use some forms of transport (e.g., driving a car) but can still get around in the community by using other forms of transport without help 3
- **Moderately:** Definite changes in use of transport, but after training can travel around the community on my own 2
- **A lot:** Need assistance to plan use of transport, but with such help can travel around the community on my own 1
- **Extreme:** Very restricted in use of transport, but with supervision can make short, familiar journeys around the community on my own (e.g., going out to the local shop) OR am unable to go out into the community alone 0

12. **Accommodation:** Has your living situation changed due to the injury?

- **Not at all:** Same or better. 4
- **A little:** Live in the community, but with emotional or social supports provided by other people, such as family, friends or neighbours. Cannot be left alone without supports for a two-week period 3
- **Moderately:** Definite changes and cannot be left alone for a weekend unless someone was available to check everything was OK 2
- **A lot:** Live in the community but in supported accommodation, such as a group home, boarding house, transitional living unit, in family home but require daily supervision or assistance 1
- **Extreme:** Almost unable to live in the community, even with daily supervision or assistance OR need care which may be at home requiring extensive, daily supervision or other care OR in an institution, such as a nursing home, residential service, rehabilitation unit 0

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