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SOCIAL IMPACT OF TRAUMATIC BRAIN INJURY IN ADOLESCENTS: A MIXED
METHODS STUDY WITH A FOCUS ON RURAL ADOLESCENTS

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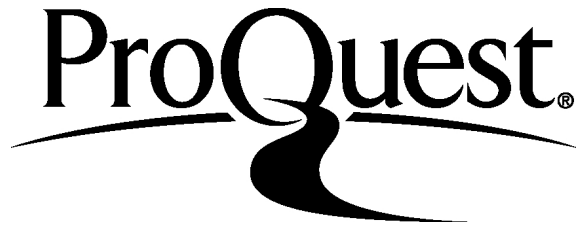
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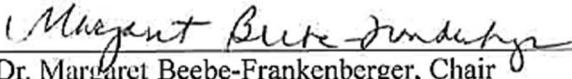
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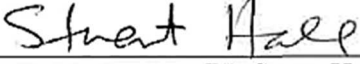
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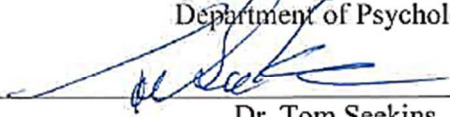
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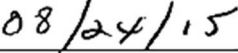
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ABSTRACT

Pediatric Traumatic Brain Injury (TBI) is a serious public health concern in the United States. The least studied populations are those at the highest risk to sustain a TBI, specifically, youth, and especially those living in rural areas. Despite the documented negative impact on social outcomes and relative importance of social functioning in youth, research is sparse with regard to how various injury and non-injury factors interact to influence social outcomes and how best to assess this population for intervention planning and monitoring. Participants are four adolescents who have had TBIs of mild or moderate severity and their mothers (three mothers). A remotely administered assessment battery that may be facilitative for rural populations is used for direct assessment of cognitive and social functioning. Quantitative findings are integrated into qualitative analysis to explore the relationship between individual, geographic, injury, and therapeutic factors on social outcomes following pediatric TBI. Primary aims of this study include piloting a brief assessment battery that can be administered remotely, assessing resources being accessed and barriers to accessing services for rural adolescents, and understanding the social effects of TBI from the lived experiences of adolescents with TBIs and their families. Results suggest distance assessment is feasible, well accepted, and potentially useful. A model is developed to conceptualize social processes following pediatric TBI for rural youth. The model provides a framework for meeting the social needs of adolescents who have had a TBI through assessment and intervention that harnesses environmental resources, mobilizes facilitators of change, and reduces inhibitors of change.

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CHAPTER 1

INTRODUCTION TO THE STUDY

Overview of Research Topic

Traumatic Brain Injury (TBI) is the most common cause of death and disability among children and adolescents in the United States (Hanten, et al., 2008). Even mild TBIs can lead to significant negative outcomes years after the occurrence of the injury (Anderson et al., 2012). Despite the prevalence, guidelines for the treatment of childhood TBI are not well-defined and do not have a sound empirical foundation (Yeates, 2008). Additionally, valid outcome measurements are not well-established, leading to difficulty assessing the efficacy of treatment efforts (Center for Disease Control and Prevention, 2014).

Among the myriad of negative outcomes associated with childhood TBI, social difficulties are one of the most commonly reported problems. Social difficulties experienced by individuals who have had TBIs include difficulty getting along with others and problems with friendships (Brenner et al., 2007), and difficulties with cognitive processes underlying social interactions (Yeates et al., 2004).

Social and behavioral outcomes have been studied and found to be significantly worse in children with TBI compared to study control participants, including those with orthopedic injuries (Yeates, 2008). However, to date, research in this area is often limited by overreliance on behavior rating scales (Rosema, Crowe, & Anderson, 2012). Direct measures of social cognition, as well as neuropsychological functioning, demonstrate better sensitivity in identifying difficulties in social functioning for children and adolescents with TBI (Rosema et al., 2012). However, most current measures are time consuming and require in-person

administration. This is potentially a barrier for those living in rural areas to properly identifying, treating, and monitoring of children and adolescents with TBI.

Outcomes for adolescents with TBI are influenced by a multitude of factors (CDC, 2014). Injury location and severity are important predictors of outcomes; however, they fail to account for over half the variance in outcomes (Yeates, 2008). Non-injury influences remain poorly understood. Unlike cognitive recovery, behavior problems tend to worsen during the first year post-injury, and it has been shown that poor behavioral trajectory is related to both pre and post injury family functioning (Yeates, 2008). In addition to family functioning, other non-injury related factors are associated with the rates of acquisition of TBI and subsequent recovery, including rural status (Spearman, 2007) and access to services (Howell & Mcfeeters, 2008). The exact mechanisms by which these factors influence outcomes, especially social outcomes, remain largely unexplored, as are factors moderating these relationships, including various intervention efforts.

Pediatric TBI is a serious public health concern in the United States. The least studied populations are those at the highest risk to sustain a TBI, specifically, youth, and especially those living in rural areas. The impact of TBI in youth involves a complex interplay of physical, cognitive, social, and psychological factors in a developmental context. Despite the documented negative impact on social outcomes and relative importance of social functioning in youth, research is sparse with regard to how various injury and non-injury factors interact to influence social outcomes and how best to assess this population for intervention planning and monitoring.

This study samples rural adolescents and their families and pilots a remotely administered assessment battery that may be facilitative for rural populations. Qualitative and quantitative

methods are used to research the relationship between individual, geographic, injury, and therapeutic factors on social outcomes following pediatric TBI. The study also examines the types of services provided for adolescents with TBI. Clarifying these relationships is a necessary step to building a foundation for the development of effective service provision, interventions, and surveillance efforts.

Specific Aims

The three primary aims of this study include the following: 1) pilot an assessment battery, sensitive to adolescent TBI and intended to target social functioning and related variables, that can be administered at a distance, 2) assess resources being accessed and barriers to accessing services for rural adolescents, and 3) in-depth exploration of the social effects of TBI from the perspective of adolescents with TBIs and their families.

Procedures Used

This study uses a small sample of adolescents and their parents living in rural areas. Participants are four adolescents and their mothers (three mothers). All participants were recruited through the Brain Injury Alliance of Montana and have had TBIs of mild or moderate severity.

This study uses a combination of qualitative and quantitative methods, but relies more heavily on qualitative methodology. Quantitative methods involve direct assessment of adolescents using a combination of rating scales and questionnaires, as well as direct assessment using telehealth software. All measures were administered remotely by either mail or electronically.

Following the initial assessment, the adolescents and their mothers participated in interviews. Interviews covered topics related to the assessment battery used in this study, needs and resources desired and accessed, and social processes following injury. The process of interviewing and analysis was conducted using a grounded theory framework (e.g. Glaser & Strauss, 1967) and quantitative data were incorporated into the analysis.

Contributions to Theory and Practice

To the best of my knowledge, this is the first study to explore social change processes from the perspective of adolescents with TBI. Furthermore, this study employed some quantitative measures, using triangulation of family members (parent-child dyads) and methods (quantitative and qualitative) to validate interpretation of findings. The measures used for this study included traditionally used instruments, as well as experimental measures, and were selected based on contemporary TBI and social impact paradigms.

In terms of assessment, this study demonstrates that a remotely-administered battery that is grounded in current research and theory is feasible and acceptable by participants. This type of assessment may be particularly useful for individuals living in rural areas who have difficulty accessing expertise or who experience other barriers to high quality assessment. The added convenience of utilizing remote methods may also enable better monitoring of changes over time and can be used to evaluate the effects of intervention in practice or research, although future research should evaluate the measures' utility in that regard. Ongoing connections between professionals and adolescents with TBIs and their families may have the collateral effect of providing a sense of ongoing support which may further advance recovery and/or adaptations.

Results of questionnaires and interviews revealed many needs expressed and services accessed. For the majority of the adolescents and families, their needs were commonly reported as met. However, unmet needs and difficulty accessing services were also expressed by most of the participants. Educational needs were the most commonly expressed needs and interview results suggested ways in which schools were meeting those needs and implications for how to improve service provision and responsiveness.

In depth interviews produced a multifaceted model of interrelated social processes expressed by participants in the study. The resulting five component model of social process following TBI provides guidance for both researchers and practitioners working with adolescents who have TBIs and captures both assets and needs as they develop over time. The model can be used more broadly as a framework for conceptualizing the relationship between immediate changes resulting from the TBI, desired changes, and factors that facilitate and inhibit those desired changes.

CHAPTER 2

LITERATURE REVIEW

Epidemiology of Traumatic Brain Injury

Unintentional injuries, most often associated with traumatic brain injuries (TBIs), are the most common cause of death and disability among children and adolescents in the United States (Langlois, Rutland-Brown, & Thomas, 2005). An average of 1.7 million TBIs are reported each year in the United States and the highest risk age groups for TBI are birth-4 years and 15-19 years of age (Faul, Xu, Wald, & Coronado, 2010). Furthermore, TBI is one of the most disabling of physical injuries and approximately 2% of the population, or over 6 million people, in the US are living with long-term disability associated with a TBI that resulted in hospitalization (Langlois, Rutland-Brown, & Wald, 2006). This is likely an underestimate however, as most of the figures available are based solely on individuals who were treated at a hospital emergency room (Langlois et al., 2006). Langlois et al. (2006) also made the critical point that TBI is associated with far greater risk for other health conditions such as binge drinking, epilepsy, and death at one to three years post injury.

Less research has been done regarding the epidemiology of pediatric TBIs. In the birth to 14 year age-group, there are nearly half a million TBI-related emergency department visits, hospitalizations, or deaths annually in the US. It has been estimated that fewer than half of the families of children who sustain a TBI seek and receive medical care for their children (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012). Yet, even with less than half of children treated, Schneier, Shields, Hostetler, Xiang, and Smith (2006) estimate the total annual health care costs associated with pediatric TBI exceed a stunning \$1 billion. An estimated 92% of

youth with reported TBI are treated and released from emergency departments (Langlois et al., 2006). The majority of this population is categorized as having a mild injury, a brief change in mental state, and is expected to make a full recovery (Langlois et al., 2006). However, many who have sustained even mild TBIs experience long-term difficulties associated with the TBI. For example, Anderson et al. (2012) conducted a 10-year follow-up with individuals who had experienced a childhood TBI. They found that of those who had a mild TBI, 25% had full scale intelligence scores more than one standard deviation below the test mean, or a standard score of less than 85 on most intelligence tests. Furthermore, 30-35% of the TBI mild group also demonstrated deficits of one standard deviation in the areas of executive skills, processing speed, working memory, and social skills. The high rate of deficits at follow-up may suggest several things, including: initial assessment may not have included measurement of these deficits, treatment may not have addressed the deficits, and follow-up during the critical three year post TBI period may not have occurred or addressed these deficits.

Despite the relatively high prevalence of childhood TBI, guidelines for treatment are not well-defined, those that are suggested and used do not have a sound empirical foundation (Yeates, 2008), and valid outcome measurements are lacking (Center for Disease Control and Prevention, 2014). In a recent report to congress, the Center for Disease Control and Prevention (CDC; 2014) highlighted the need to enhance measures of comprehensive rehabilitation success and to improve delivery models. Adding to the difficulty of both research and treatment, the adult literature suggests that rural areas have a higher rate of brain injury (Spearman, Stamm, & Tuvis, 2007), that brain injuries are more severe in rural populations than their urban counterparts (Robertson, 2010), and that individuals in rural areas are more likely to experience

barriers to treatment (Robertson, 2010; Spearman et al., 2007). Validation of the literature with respect to rural areas comes from the State of Montana, where statistics place the state second highest for death due to TBI per capita in the nation with a rate of over 30 per 100,000 (Montana Department of Health & Human Services, nd); the national average is 18.4 per 100,000 (Coronado et al., 2011).

Scope of the Problem

The impact of TBI in children is extensive and can be chronic. A wide range of deficits are experienced by children as a result of TBI in both the short and long term in such domains as academic, emotional, cognitive, psychological, and behavioral (Yeates, 2008). Deficits related to childhood TBI can emerge much later in life and can easily go unnoticed if individuals do not receive adequate information and evaluation (Brenner et al., 2007). Among the myriad of negative outcomes associated with childhood TBI, social problems are among the most commonly reported problems. Social deficits that may not be detected at an early age may manifest as difficulty getting along with others, problems with friendships, and difficulty with intimate relationships as children age and the social milieu increases in complexity (Brenner et al., 2007). These deficits in social ability may be exacerbated by neuropsychological and language deficits (Yeates et al., 2004). Furthermore, individuals with TBI may lack insight into their problems (Brenner et al., 2007; Wolfe et al., 2015); thus, they may be unreliable self-reporters and unlikely to seek help for their problems, especially if the TBI is severe (Wolfe et al., 2015).

There is ample evidence suggesting that the sphere of influence from a TBI extends well beyond the child. Importantly, the impact of child TBI on families has been shown to be greater

than that of other types of pediatric injuries (Carnes & Quinn, 2005) and there is a substantial social and economic burden, with over 200,000 children hospitalized each year (Schwartz et al., 2003). Overall, the aggregated direct and indirect economic costs in the United States for TBIs at all ages have been estimated at \$60.4 billion per year (Finkelstein, Corso, & Miller, 2006).

TBI Impact

Neuropathology

TBI is associated with multiple forms of physiological changes occurring in the brain, ranging from immediate to late-onset. Yeates (2010) describes the neuropathology of TBI in terms of four interrelated categories; primary insult factors, secondary effects, neurochemical effects, and delayed pathology. The individual and combined effects of these forms of pathology are complex and prolonged. Furthermore, the effect of TBI in children is decidedly different than in adults. Children have biomechanical differences (e.g. less myelination, greater head to body ratio) and are in a state of more rapid development. A young brain is more likely to display posttraumatic brain swelling, hypoxic-ischemic insult, and diffuse injuries (Yeates, 2010). Where it may once have been assumed that children were more resilient to head trauma than adults, it is now believed that children have an equal or worse prognosis following TBI (Hale, 2011). Although children's brains may be better able to allow short-term recovery by shifting functions to non-damaged parts of the brain, later developing abilities may be compromised (Kade & Fletcher-Janzen, 2009). Frontal and temporal poles of the cortex are particularly vulnerable to TBIs due to the rough internal topography of the skull in these regions (Bigler, 2007). These regions are vital to cognitive functions comprising executive control, memory, and language. Furthermore, problems with more integrative and subtle processes may not become evident until

these processes become critical to functioning, as might be the case as children transition to adolescence and demands on executive processes become more salient (Iverson, 2005). For injuries occurring in adolescence, the effects of TBI appear to be more similar to adults than to younger children (Yeates, 2010).

Social Impact

Human's physical and psychological health is dependent upon social relationships across the lifespan, and disruptions to social relationships are among the most stressful life events endured (Cacioppo, 2002). Sudden disruption to social ability can result in psychological distress, social isolation, reduced self-esteem, and can significantly impact quality of life (Beauchamp & Anderson, 2010).

The importance of social interaction cannot be overstated, and several levels of analysis are available to examine social interaction and competence. Cacioppo (2002) argues convincingly that the study of social behavior can be made more complete through the integration of social, cognitive, and biological levels of analysis, and the literature on social outcomes of TBI is well represented by each level. The nature of TBI as a physiological disruption lends itself to a biological level of analysis; however, findings in the general TBI literature suggest that variables related to injury severity and location fail to account for over half the variance in outcomes (Yeates, 2008), and in long-term studies the variance explained by injury related factors may even be non-significant (Anderson et al., 2011).

Brain injury in children often results in problems with social functioning and poor social outcomes persist over time (Andrews, Rose, & Johnson, 1998; Yeates et al., 2014). The vast majority of research findings in social outcomes following TBI are attenuated by analyses

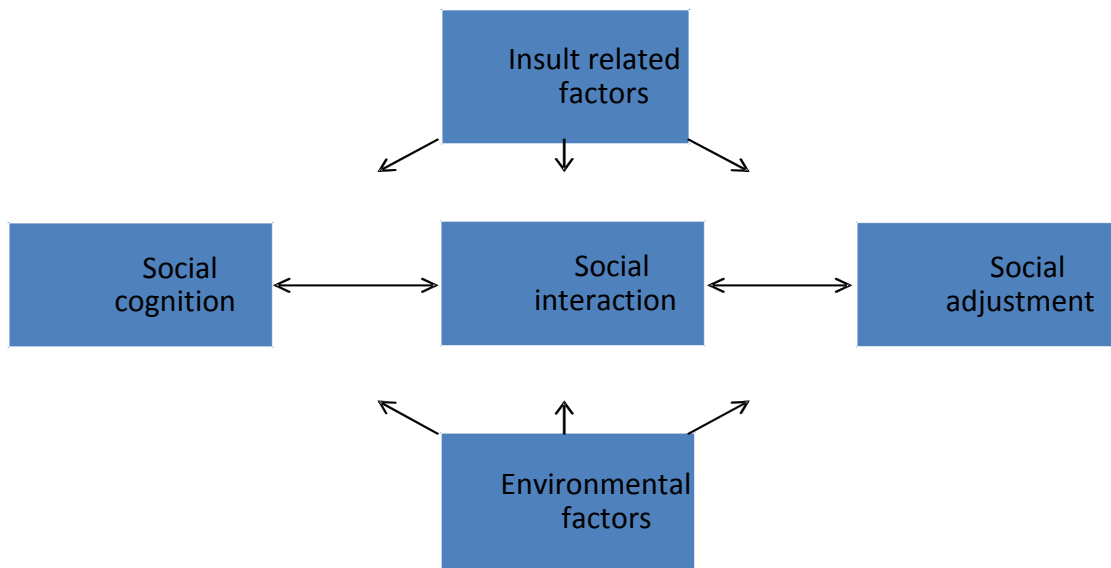
involving shared rater and method variance, resulting from the use of behavior rating scales (Rosema, Crowe, & Anderson, 2012). Alternatively, recent evidence has suggested that direct measures of neuropsychological functioning can measure underlying cognitive deficits that contribute directly to social functioning. For example, increasing attention in the field has been given to investigating the neural underpinnings and resulting mental operations underlying social function (Beauchamp & Anderson, 2010). An implicit assumption in this line of research is that early disruption to neurological development has the capacity to derail both social functions and their underlying neural substrates (Rosema et al., 2012). For example, one often used model of social cognition, the social information-processing network model (SIPN), proposes three interrelated neurocognitive networks (Nelson, Leibenluft, McClure, & Pine, 2005). In this model, portions of the temporal cortex are involved in social stimuli detection, affective processes are handled largely by medial temporal lobe structures, and portions of the pre-frontal cortex are responsible for cognitive and regulatory functions. During adolescence, the SIPN undergoes significant changes reflected in, and facilitated by, social behavior changes; the SIPN represents the type of relationship between maturational, development, and behavioral outcomes physiological disruption may engender. A number of theoretical models have been developed to conceptualize multifactorial social effects of TBI from both distal and proximal influences in a developmental context.

Nomenclature between models varies; however, terms are often conceptually similar. Primary categories of social domains present in several models can be captured in the terms “social adjustment”, “social interaction”, and “social cognition” (e.g. Beauchamp & Anderson, 2010; Yeates et al., 2007). Social adjustment can be defined as, “the extent to which children

attain socially desirable and developmentally appropriate goals” and encompasses the quality of children’s relationships (Yeates et al., 2007, p. 537) and overall performance across domains (Yager & Ehmann, 2006). Social interaction refers to the actions and reactions of individuals or groups in response to a particular situation (Beuchamp & Anderson, 2010) and includes those cognitive, verbal, and nonverbal behaviors needed to have positive interpersonal interactions (Yager & Ehmann, 2006). Social adjustment is often used as the chief outcome measure, whereas, social interaction is often considered an intermediary between social cognition and penultimate outcome. Social cognition is a unique domain of cognition encompassing the reception and processing of information used to inform a social response (Yager & Ehmann, 2006). The relationship between and among these levels of influence are illustrated in Figure 1.

Figure 1

An integrative multilevel model of social competence in children with brain disorder (adapted from Yeates et al., 2007)



Each of these levels of analysis is represented in the literature and describes effects of pediatric TBI on social functioning. In a systematic review of current findings with regard to social functioning and TBI, Rosema et al. (2012) examined 28 articles published in the last 23 years. They concluded that the bulk of the evidence confirms what had long been clinically suspected; children and adolescent survivors of moderate to severe TBI are at an elevated risk for social impairment. Definitive conclusions, however, were clouded by methodological issues, including overreliance on parent report.

Interestingly, the Rosema et al. (2012) review found similar numbers of studies finding no significant group differences in social adjustment between those with TBI and controls as

studies that found significant differences when parent reports were the primary outcomes measures. In the few studies they found that incorporated direct child measures, social deficits were found. They also found the impact of injury severity to be unclear. Similar discrepancies were found with regard to social interaction. Of the few studies reviewed that addressed social interaction, only Prigatano and Grupta (2006), using open questions to parents, found significant deficits in this area. Social interaction deficits have also been demonstrated using peer rating methods (Yeates et al., 2013) and in long-term follow-up using self and close other ratings of social communication (Ryan et al., 2013). Clearly, studies using social outcomes measures that go beyond parent report are needed to clarify these discrepancies.

Findings from research using direct and indirect measures of social abilities suggest that using more direct measurements may be much more predictive of social functioning than using exclusively rating scales and global observations. Recent evidence suggests that direct measures of neuropsychological functioning can measure underlying cognitive deficits that contribute directly to social functioning. Of the three hypothesized levels of social performance, Rosema et al. (2012) found social cognition to be most consistently impaired. The studies investigating social cognition commonly used direct assessment methods of the child. Domains of assessment included theory of mind, emotion perception, executive functions, and social problem solving. Results of the review generally supported the social cognitive domain of social problem solving as a mediator between more general executive functions and social outcomes, but some reviewed studies supported the direct predictive capacity of measures of executive function alone (e.g., Yeates et al. 2004).

Ganesalingam et al. (2011) demonstrated that direct measures of executive functions, such as response inhibition, working memory, pattern recognition, and mental flexibility were related to behavioral ratings of inhibitory control and attentional focusing. These behavioral measures, in turn, were strongly associated with social interaction. More direct measures of social cognition show even greater promise. Social problem solving measures have demonstrated the ability to differentiate between children with TBI and those with orthopedic impairments (Ganesalingam et al., 2010) and have proven sensitive to particular neurological deficits incurred in TBI (Hanten et al., 2008). They also have demonstrated that performance on measures of social problem solving are related to both parent and teacher ratings of social adjustment and behavioral regulation (Ganesalingam et al., 2010; Yeates et al., 2004; Janusz, Kirkwood, Yeates, & Taylor, 2002). These findings suggest that social cognition may be a level of analysis that is both meaningful in terms of predictive utility and sensitive to the effects of pediatric TBI. However, the relationship between performance on social problem solving tasks and other social outcomes remains an area of debate. Some research has found that direct social cognition measures may be sensitive to brain damage but not related to social interaction (Hanten et al., 2008), while others have used rating scales instead of direct measures for social cognition (e.g., Muscara et al., 2008). More precise measures of social cognition and their relationships with other measures and outcomes is an area of great need if we are to understand the impact of TBI on social functioning of young people.

Determinants of TBI Outcome

Injury Related Factors

In their review of the literature, Rosema et al. (2012) identified several factors that have been shown to be predictive of social outcomes following TBI in childhood: injury severity, age at injury, location of brain damage, and environmental factors. Severity of injury is one of the most studied predictors of social outcomes. Prigatano and Grupta (2006) demonstrated partial support for a dose-response relationship for TBI severity and number of friends, with decreasing numbers of children reporting *four or more* friends as severity increased. This relationship was not always linear, however, and children categorized as having mild TBI were equally as likely to have 0-1 friends as children categorized as having severe TBI. A lack of linear dose-response relationship is consistent with the general TBI literature suggesting the importance of non-injury related factors as determinants of outcomes (Yeates, 2008). Nevertheless, Prigatano and Grupta (2006) found the percentage of children in the severe TBI category whose parents reported that they had four or more close friends was 14%, compared to 39% of the mild TBI group and 75% of the trauma controls. Chapman et al. (2010) found social impairment in their severe TBI group but not in the moderate TBI group, and Muscara, Catroppa, Eren, and Anderson (2009) showed that children who suffered mild TBI functioned better socially than moderate and severe TBI groups.

In general, age of injury tends not to be strongly associated with outcomes for school-aged children. However, for children who are preschool-aged and younger at the time of injury, TBI tends to be associated with worse outcomes (Yeates, 2008; Garcia, Hungerford, & Bagner, 2015). Although very little research has looked at social outcomes and age of injury in children,

Sonnenberg, Depuis, & Rumney (2010) studied 8-year-old children with moderate to severe TBI and found that children under the age of four at the time of the TBI had worse parent reported social outcomes than those who were older at the time of injury, and a recent review of the literature suggested that TBIs that occur before the age of five tend to result in worse cognitive and behavioral outcomes (Garcia et al., 2015). Direct measures of social functioning may prove more fruitful in identifying age-related differences in social abilities. Ryan et al. (2015) found that children age 5-9 tended to maintain deficits in pragmatic communication two years post-injury, while older children and adolescents returned to age-expected levels.

Time since injury is, perhaps surprisingly, not consistently related to social functioning. Yeates et al. (2004) found that parent reports of social functioning tended to worsen during the first year post-injury, and then stabilize, with little improvement over time. This finding is consistent with findings of studies from other behavioral domains which, unlike cognitive abilities, tend to worsen in the post-acute phase of recovery in pediatric TBI (Fay et al., 2009).

Hanten et al. (2008) demonstrated that brain lesion (brain tissue damage as a result of injury) characteristics, including location, had little relationship with performance on social problem-solving overall; although, they did find poorer performance related to frontal lesion presence for children younger than 12 at the time of injury, which they attribute to disruption of this later developing region of the brain. They were able to find stronger relationships with structural integrity, reflecting the tendency for problems associated with pediatric TBI to be primarily related to diffuse axonal injury. Taken together, these studies indicate several injury related factors have some association with social outcomes, but results of studies are often inconsistent.

Non-Injury Related Factors

Family functioning. Several factors not directly related to the injury characteristics have been demonstrated to be influential to social outcomes following pediatric TBI (CDC, 2014). Chapman et al. (2010) found that several non-injury factors were significantly related to a combination of social and behavioral parental ratings. Significant factors in their study included socioeconomic status (SES), poor family functioning, and parenting style. The influence of SES has been supported in other studies as well (Muscara, Catroppa, Eren, & Anderson, 2009). Potter et al. (2011) found that pre-injury parenting style and family resources were related to behavioral ratings of executive function. Given the strong relationship between ratings of executive function and ratings of social competence by parents of children with TBI (Ganesalingam, 2011), this finding would support the influence of family factors on social behavior. Yeates et al. (2010) however, examined behavior and social functioning separately and found that family environment was related to behavior problems, but not necessarily to social outcomes. Each of the studies cited here examined exclusively young children aged 3-7 years. Relatively little research has examined family factors as a predictor, mediator, or moderator of social functioning in older children and adolescents with TBI. Micklewright, King, O'Toole, Henrich, & Floyd (2012) demonstrated that parent distress was associated with adaptive functioning (including social functioning) and parenting practices mediated the relationship between parent distress and children's adaptive functioning, and others have found similar findings with regard to behavior (Woods, Catroppa, Barnett, & Anderson, 2011). Parenting practices, in turn, may be related to parent emotional state and parent relationship to their own internal state (Brown, Whittingham, & Sofronoff, 2015).

Diversity. Little attention has been paid to issues of diversity in pediatric TBI despite the relationship they may have with other non-injury factors shown to contribute to social outcomes, such as parenting style, family social support, and SES. National data on race and ethnicity suggest that there are vastly different rates of deaths by TBI between groups with the highest rates in the American Indian/ Alaska Native population: an age adjusted rate of 27.3 deaths per 100,000 compared to a rate of 18.4 for combined race/ethnicity (Coronado et al., 2011). There may also be differences between cultural groups in their acceptance and response to psychosocial interventions for neurologically related disorders (DeVries & Morris, 2008). This research study is particularly concerned with geographic diversity and the role rurality may play in social outcomes.

Rural status. Rurality is a risk factor for the acquisition of TBI as well as for rehabilitation. As previously mentioned, rural residents are at greater risk for TBIs. Evidence suggests that those in rural areas are among the most at risk for low quality of life and difficulty obtaining needed supports and services (Spearman, 2007). Furthermore, SES is a significant risk factor which tends to be lower in rural areas (Yellowlees, Marks, Hilty, & Shore, 2007). Additionally, guidelines for diagnosis and treatment of behavioral health problems often do not take into account the unique features of rural areas (Frontier Education Center, 2003), such as limited availability of mental health professionals, lack of anonymity, poverty, availability of specialty services, and the availability and type of social support.

Socioeconomic status. In 2013 about 26% of rural children lived in poverty (United States Department of Agriculture) and many of them do so with no insurance (Nordal et al., 2003). Implications of this situation are multifaceted. One implication is that specialty

healthcare providers and mental health providers may be unattainable due to financial reasons. Another implication of poverty is that it places great stress on the family unit (Conger, Elder, Lorenz, Simons, & Whitbeck, 1994). According to U.S. Census data, children living in rural areas are more likely to live in larger families (2006), have married parents (2011), and have parents who both work (2000). So, there is great potential in the family configuration to support recovery. Research on urban/ rural differences in family structure and function are limited; however, one qualitative study of rural, impoverished, working families suggested that family and friends were the most highly regarded sources of support that families identified (Greenlee & Lantz, 1993).

Access to services. There are also several implications of rural living with regard to access to services. The adult literature suggests that people living in rural areas may be less likely to seek health-related services and wait until symptoms are worse before seeking help (Stamm, 2007). Rural children also face a number of challenges getting health and mental health care needs met, including fewer practitioners. Often, school-based services and clinics provide the only services or they function as the access point to services provision (Howell & Mcfeeters, 2008) and many school psychologists in rural areas identify limited availability of support services outside of the school and lack of program options as a challenge to practicing in a rural area (Clopton & Knesting, 2006). In the past, governmental reimbursement rates for Medicare and Medicaid have been lower for rural areas, placing rural communities at risk for attracting and sustaining medical professionals to serve whole communities. The Patient Protection and Affordable Care Act (2010) has included in it a provision for “frontier states,” including Montana, Wyoming, and South Dakota, that places a floor on reimbursement rates equivalent to

the national average. Hopefully, this act helps to make service provision a financially tenable proposition. Despite the implications of these findings, there is a dearth of research on rurality and pediatric TBI, and most studies of TBI are conducted in research facilities in large urban areas, making inclusion of individuals from rural areas problematic.

School Supports for TBI

Children with TBI do not receive many school-based services. However, parents also may not perceive a need for school-based services, even when the TBI is categorized as severe (Gfroerer, Wade, & Wu, 2008). Gfroerer et al. (2008) found that parents' requests for minor adjustments (such as to their schedule) for their children with a TBI were typically granted, but that the children infrequently received school-based counseling or behavioral support. They concluded that the greatest unmet need of children with TBI in their study was social, behavioral, and emotional support. Considering the actual risk for children with a TBI for a variety of problems, including social relationships, these results suggest the importance of carefully considered and well planned assessment and interventions. Schools, hospitals, and other professionals and organizations involved with a child who has sustained a TBI must take the appropriate steps to evaluate, consult, and ensure that appropriate supports are provided and individualized to the child's needs. Considering the trajectory of social and behavioral symptoms in particular, known to worsen over the course of the first year after injury, ongoing collaboration between members of treatment teams in and out of school is important. Ongoing progress monitoring assessment should be considered as part of the treatment plan and results communicated to parents as well as other professionals.

Comprehensive and multidisciplinary evaluation for progress during rehabilitation is important to promote recovery and enable transitions to home and school for children with TBI (Farmer, Clippard, Luehr-Wiemann, Wright, & Owings, 1996). These evaluations require specialized expertise. The types of deficits experienced by children with TBI, such as impairments in emotion recognition and theory of mind, may not be identified on the type of standardized tests used in educational settings and the highly structured nature of evaluative practices may overlook functional deficits (Ylvisaker et al., 2001; Turkstra, Williams, Tonks, & Frampton, 2008). Furthermore, specialized evaluations (e.g. neuropsychological) take into account injury characteristics and implicated deficits to predict performance and anticipate problem areas in the future (Hale, 2011). Evaluations and observations should be ongoing and multifaceted and consider that TBI related problems can arise years after the injury. This may especially be the case in respect to social impairments in children with TBIs (Hibbard et al., 2006). School staff, especially school psychologists, may be in a good position to conduct both formative and summative evaluations of academic, social, emotional, and behavioral adjustment on an ongoing basis. However, professionals specialized in neuropsychological assessments and relevant medical expertise are needed to fully evaluate recovery. Thus, collaboration between schools and other professionals and agencies is vitally important.

Early and regular communication should be made by evaluation staff to family, educators, and other specialists that work or will be working with the child (Hale, 2011). This collaboration permits clear identification of functional abilities and increases the child's potential for positive long-term outcome, including buffering against the impacts of deficits in executive functions (Galvin & Mandalis, 2009). Moreover, hospital-school communication makes it more

likely that students will receive formal and appropriate accommodations and services (IEP or 504 plan; Glang et al., 2008) in school. Despite this need, it may be that it is relatively unlikely for professionals with specialized knowledge in TBI, such as neuropsychologists, to be involved in consultation for students with TBI in schools (Bozic & Morris, 2005). Additionally, parents may not be aware of potential detrimental effects of TBI and may not be aware of school-based services that can benefit the child (Gfroerer et al., 2008) and, therefore, may not report a TBI incident to the school. This is an especially relevant consideration for social and behavioral issues that may not arise immediately following the injury.

Hale (2011) summarized evidence-based practices in transitioning children with TBI back to school and states that in the case of children who have a significant hospitalization, team planning should occur before a child's release from the hospital and should include school personnel. Prior to this planning, the child's hospital team should be familiar with the school environment and may be involved in teacher interviews and school observations. This interdisciplinary collaboration is critical for successful transition and establishment of effective services, but does not often occur (Hibbard et al., 2006). Many of these children will require special education support and their IEP should reflect findings of hospital and neuropsychological evaluations. Formalized plans for reintegration and support are likely less prominent for those students with less severe injuries and for those in rural areas. In a survey of high school principals across one Midwestern state, 32% of the principals reported that they have written plans provided to parents for students with concussion, but written plans were less common in smaller schools (Heyer, Weber, Rose, Perkins, & Schmittauer, 2015).

Currently, there is a lack of professional consensus on intervention for students with brain injuries and limited evidence of effective school-based practices to improve social functioning in children with TBI (Taylor et al., 2003; Yeates, 2008). However, some initial findings highlight promising practices for the social supports. In a qualitative study of children with TBI aged 5-15 and their families, Berbaum (2007) found that increased meaningful peer relationships were among the most important unmet needs. Medical sequelae usually resulted in special education placement that was non-inclusive and of indefinite duration, demonstrating that children with severe TBI are not receiving services that facilitate a normalized educational experience and may be placed in environments where peer exposure is minimal. Multiple studies have found that school psychologists and educators evidence a lack of professional knowledge and/or experience in working with children with TBI (Berbaum, 2007; Hooper, 2006). Rural areas in particular might have limited placement options and lack opportunity to collaborate with university and medical settings (Berbaum, 2007; Clopton & Knesting, 2006). For children in more inclusive settings, positive social change was perceived by families and educators to be associated with increased classroom integration and functional independence, normalization of classroom experience, and decreased marginalization. Families generally desired more inclusion for their children. Furthermore, it is important to note that cognitive and academic gains can occur in the context of deteriorating behavioral functioning following pediatric TBI (Fay et al., 2009). Given the increased risk for behavioral and social problems following TBI, it is important for professionals working with families in schools to attend to these domains independently of academic performance alone.

Contribution of Qualitative Research

The primary purpose of qualitative research is to capture of the meaning of psychological phenomenon and relationships among variables as they occur naturally. The aim of qualitative research is to capture *emic* or insider's view, instead of the *etic* or outsider's view (Nastasi & Schensul, 2005). From this perspective, research findings are considered to be context or culture-bound, not necessarily generalizable.

Natasi and Schenul (2005) argued for the importance of qualitative research in translational research, dissemination, and intervention. They stated that extant research in child intervention is fraught with problems involving a lack of attention to cultural and contextual factors that facilitate or inhibit the effectiveness of intervention and influence social validity of strategies designed to ameliorate problems. They also argued that the majority of intervention research is based on quantitative extrapolation and is limited in the formative incorporation of the target population perspective, including children, schools, parents, and community organizations. Qualitative research methods promise the patient perspective and the potential to ameliorate many common research shortcomings in conceptualizing change, designing interventions and measures, and translating research-to-practice. As Crisp (1994) put it, qualitative research, "Enables respondents to act as co-participants which underlies the need for a more egalitarian relationship between research and respondent." (p. 20)

There has been a dearth of qualitative research on TBI in children and far less that takes the child's perspective. However, important contributions to literature on social outcomes following TBI have been made. A considerable amount of qualitative research has been conducted on TBI in adults, and the qualitative research conducted on adults has added

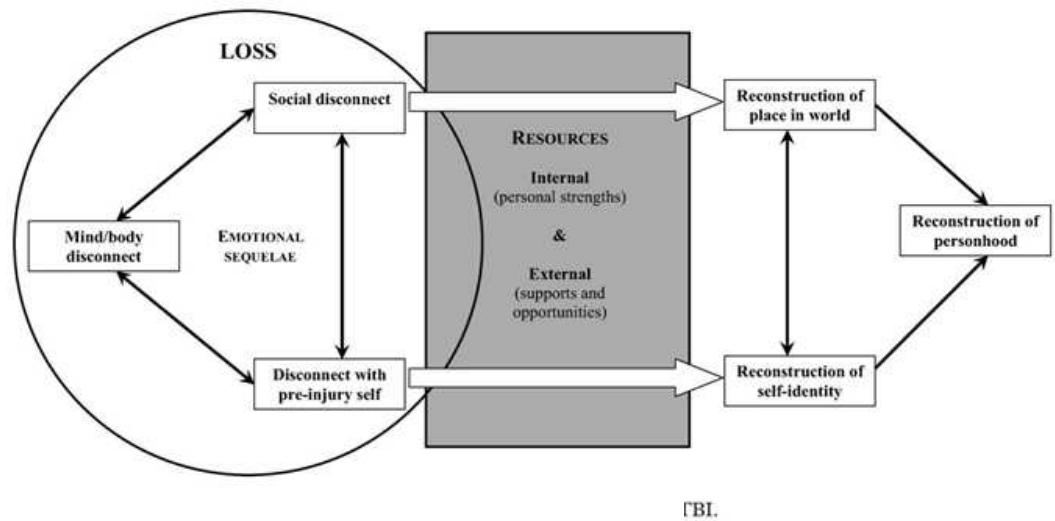
tremendously to both research and practice in recovery process, social functioning, and patient concerns. Additionally, some research has been conducted that uses various mixed and qualitative methods to investigate parent and children’s perspectives on TBI, recovery, and social processes. These studies are described below.

Adult Models of TBI Experience

Levack, Kayes, and Fadyl (2010) conducted a metasynthesis of qualitative research on the “lived experiences” of adults who acquired TBI in adulthood. They analyzed the results of 23 qualitative studies on the topic. They identified eight inter-related themes: 1) mind/ body disconnect; 2) disconnect with pre-injury identity; 3) social disconnect; 4) emotional sequelae; 5) internal and external resources; 6) reconstruction of self-identity; 7) reconstruction of a place in the world; 8) reconstruction of personhood. The relationship among these variables is shown in Figure 2.

Figure 2

Metasynthesized model of the lived experiences of adults with TBI.



Notably, the authors raise the issue of measurement in research and clinical practice. They identified a lack of outcomes measures that address several of these common themes, including loss of personal identity, reconstruction of self-identity, and reconstruction of personhood. These three themes are conceptualized as central processes involved in outcomes following TBI from the perspective of the individuals with TBI (depicted in Figure 2) and were identified as deeply troubling for many of the participants in these studies. Examples of these themes that are not captured in typical measures include the extent to which family, friends, and community helped to create and support opportunity for a new identity was identified as important for successful outcomes.

Although this research is very broad in scope, it illustrates several important aspects of current research. Relationships among variables are complex and multifaceted and are inextricably tied to multiple inner and outer contexts. Such relationships are difficult to capture using traditional quantitative methodology. Furthermore, although a myriad of research exists in adult TBI, important aspects of the patients experience have likely not been taken into adequate consideration. In terms of external resources, several examples identified through the meta synthesis might theoretically be difficult to achieve for rural adolescents due to the unique social and physical context. Opportunities to engage with peers who have TBI may be difficult or impossible to achieve in a traditional sense (face-to-face engagement). Some may be different in nature, such as opportunities to try activities and explore limitations and abilities

Qualitative research has also demonstrated that, when the patient perspective is considered, there may be less concern with those aspects of injury and processes that are often the focus of quantitative research. Lennon et al. (2014) compared adults with Acquired Brain

Injury (ABI) to adults with Spinal Cord Injury (SCI). Both groups had a positive self-narrative composed of the experience of having the injury contributing something positive to their personal identity and purposeful actions that occurred as a result of the injury that promoted their self-reconstruction. They also found opposing processes to occur. Individuals in both groups reported that the injury experience led to a negative view of self and an inability to continue with identity-related roles. They concluded that the experiences of both groups reflect the same themes, including what they call the “paradox of self,” which is the experience of the self as simultaneously changed and continuous. Their findings suggest that individuals construct both positive and negative narratives. They also described what they termed the “paradox of self;” that participants experienced their sense of self as simultaneously changed and continuous. These concerns and processes stand in stark contrast to the emphasis in the bulk of the literature on the relationship between organically altered cognitive and emotional functioning often assumed to underlie changes in social functioning.

Qualitative Research of Social Experiences

Prior research using qualitative methods has been very broad (e.g. focused on the entirety of experience), such as the qualitative research summarized above, although several of the findings have direct implications for social processes. For example, Lennon et al. (2014) found several aspects of positive self-reconstruction that were related to social processes, including appreciating existing relationships, meeting new people, and relating self to others strategically. One aspect of negative self-reconstruction was clearly social in nature, being a burden on others. The present study uses existing theoretical models to probe deeper into specific aspects of this lived experience from two different perspectives (parent and adolescent), attempting to delineate

the nature of the relationship rural context (external supports and opportunities in the Levack model) and social outcomes (as one part of a holistic conceptualization of outcome).

Some of the adult TBI literature has specifically examined social aspects of TBI.

Hammond, Davis, Whiteside, Philbrick, and Hirsch (2011) conducted focus groups with spouses of individuals who had TBIs. Using a model of relationship dynamics, they found that TBI led to changes in family dynamics and changes in spouses' perception of those dynamics that both helped and hurt marriages. Spouses reported that the injury affected roles, responsibilities, trust, communication, and behaviors. Using a series of interviews over 12 months, Crisp (1994) identified different patient attitudes toward recovery and the impact that TBI had on those attitudes as being strongly related to social process. Results of their study suggest that individuals' attitudes toward their injury can range from entrenched in the disability to attending to the positive aspects of the injury, and that their position on that continuum dictated the degree to which they sought out and enjoyed social interactions. They also found that differences in the nature of social support was important in determining quality of participants social experience, such that accepting, positive, and helping relationships facilitated high social satisfaction. Kinsella et al., 1988, used interviews to demonstrate that individuals with TBI reported less quantity of social relationships, but no decrease in quality of social relationships. Considering the robust findings related to social deficits following TBI, intact quality of social relationships was unexpected. It was unclear from their research if limited insight into social relationships was present and could account for reported quality of relationships.

Qualitative Research Involving Children and Families

A few studies have used qualitative and mixed methods to specifically examine children and social functioning in children. Prigatano and Gray (2007) used a mixed methods approach to qualitatively analyze verbatim responses written on behavior rating scales completed by parents of children with TBI. They found that parents who reported high levels of parenting stress indicated social skills and friendships among primary concerns. Furthermore, high levels of concern and stress were found at all levels of injury severity. Donovan, Mehringer, and Zeltzer (2013) interviewed children who experienced migraines along with their parents and medical providers who work with children who have migraines. Substantial variation between groups of participants in emerging themes related to social functioning was observed. Child-identified themes were the need to be alone, lack of sibling support, and lack of understanding by others. Parent themes centered on family responsiveness and feelings of inadequacy, and clinician themes related to parental involvement and adolescent schedules.

Qualitative Investigation into Assessment Modality

Qualitative methods may also be used to evaluate assessment methods. There is an increasing push toward the incorporation of children's perspectives into the creation of outcomes measures (Arbuckle & Abetz-Webb, 2013) but less research in evaluating mode of delivery. In a good example of the utility of such an approach, Engan, Chenoweth, and Mcauliffe (2006) used a combination of unstructured observations and specific questions on interview methods to evaluate the use of email-facilitated interviewing for adults with TBI. This methodology enabled them to identify positive and negative aspects of email as an interview method from both the participant and researcher's perspectives.

The above studies highlight the promise and utility of using qualitative methods in research on TBI and children's recovery, social outcomes, and to gain insight in patient perspectives. However, it also highlights the many gaps in the literature and suggests several unanswered questions, including: Do models of TBI experience in adults apply equally well to children? How does rurality impact the relationship between external context and social identity development? Do the tools we use to measure important outcomes match the experiences of children with TBI and their families? How is a parent-child relationship impacted, and how does it effect socialization? The present study adopts a primary perspective concerned with the experiences of the adolescents and families participating, thus, is not directly testing any of the above research questions. However, it is hoped that through a sufficiently broad sampling of parent and adolescent experiences related to injury and social functioning, some of these gaps will begin to be filled. The present study integrates qualitative and quantitative methods to pilot a remote assessment battery and uses interviews with adolescents with TBI and their parents to explore the social effects of TBI and resource use.

In summary, TBI is not uncommon, especially in adolescents. Rural adolescents may be at more risk than their urban counterparts, yet are underrepresented in research and their unique needs are not accounted for in traditional assessment and treatment paradigms. Social problems are common among children and adolescents with TBI. While many contributing factors have been identified with regard to social outcomes following pediatric TBI, little research has examined social processes from the perspective of the adolescents with TBI and their families. One underlying premise of the present study is that understanding the experiences of adolescents with TBI and their families will enable a better understanding of how previously identified factors

interact to create the social processes experienced by this population. Thus, this study has three primary aims; 1) pilot an assessment battery, sensitive to adolescent TBI and intended to target social functioning and related variables, that can be administered at a distance, 2) assess resources being accessed and barriers to accessing services for rural adolescents, and 3) in-depth exploration of the social effects of TBI from the perspective of adolescents with TBIs and their families. A mixed methods approach is used to accomplish these aims.

CHAPTER 3

METHOD

Prior to a description of the methods for data collection in the present study, background information is provided about mixed methods, qualitative research, and use of qualitative methods with child subjects. The information supports the research design and methodology of the present study.

Mixed Methods Research

The differences between qualitative and quantitative research are often described in terms of fundamental assumptions regarding knowledge and inquiry. A quantitative approach is thought of as being applicable to a positivistic world view, which assumes cause-and-effect relationships, seeks to isolate these relationships, and is based on numeric measures (Creswell, 2009). This is contrasted with constructivism in which meaning and knowledge are assumed to arise from subjective experience and interpersonal interaction (Lincoln & Guba, 2013). Constructivist inquiry stems from the belief that social reality can only be understood relative to individuals in a context (Lincoln & Guba, 2013). Qualitative methods are used to understand reality in this paradigm.

Qualitative and quantitative research methods remain attached to their respective conceptual paradigms (Johnson, Onwuegbuzie, & Turner, 2007). Historically, it has been thought that due to competing paradigms, the use of both methods in one research project was theoretically flawed on the basis of irreconcilable philosophic and epistemological foundations (Campbell, Gregory, Patterson, & Bybee, 2012). In more recent years there has been a shift away from solely qualitative or quantitative research toward placement on a continuum between the

two (Creswell, 2009). Mixed Methods is the name given to a broad range of research designs incorporating elements of both positivist and constructivist epistemologies and derived investigation techniques. Johnson et al. (2007) proposed this definition:

Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration (p. 123).

The authors summarize a contemporary philosophical stance on mixed methods research as pragmatism; the use of methods that best answer the research question. Pragmatism as a unifying framework remains a topic of debate in mixed-methods research (Hesse-Biber, 2015), but offers an alternative that is suitable for a wide range of mixed methodology. A mixed-methods approach should be used when it is likely to provide the most suitable answer to the question(s) being asked (Johnson et al., 2007).

Mixed methods are indicated when studying complex phenomenon in context and capitalize on the unique perspective afforded by both quantitative and qualitative methodologies (Campbell et al., 2012). Importantly, mixed methods research is based on an appreciation of sociopolitical and local context, needs, and resources (Johnson et al., 2007). Some of the advantages advocated in the literature for use of mixed methods include its utility for triangulating findings, clarifying or elaborating on a given issue or finding, using of one method to inform the other (Green, Caracelli, & Graham, 1989), engaging community members, and improving instrument validity (Collins, Onwuegbuzie, & Sutton, 2006). As Torrance (2012)

stated with regard to the importance of incorporating qualitative methods and philosophical stance into traditionally quantitative paradigms, “qualitative approaches offer greater purchase on the complexities of social life and greater opportunities to involve research participants in studies, which may shape the conditions under which they live” (p. 118).

Mixed methods research often has been used for the purpose of comparing and contrasting findings from multiple methods, corroborating findings and conclusions drawn from obtained data. The quest for a convergence of findings is referred to as triangulation and is a key principle in mixed methods research (Torrance, 2012). Several aspects of triangulation have been articulated, including, triangulation of data, investigators, methods, and theory (Denzin, 1978).

The present study adopts a pragmatic philosophical stance and is more heavily influenced by qualitative methods than quantitative. Mixed methods are used as one source of triangulation. This study uses triangulation of methods (direct measures and interviews) and triangulation of subjects (parent and adolescent) by quantitatively summarizing abilities and context, then interviewing both parents and their children.

Qualitative Methods

The role of the qualitative perspective in mixed methods research has been a source of debate, with some researchers claiming that mixed methods research often assumes a position of positivism and overemphasizes a quantitative stance (Hesse-Biber, 2015). Despite a possible overemphasis on quantitative frameworks, many qualitative techniques have been used in mixed methods research. The approach utilized in the current study is a grounded theory approach. A grounded approach cannot, necessarily, be conceptualized as a unitary method (Henwood & Pidgeon, 2003). Grounded theory originated in the work of Glaser and Strauss (1967) and arose

from dissatisfaction with the creation of abstract theories and the perceived lack of relevance of quantitative research to the experiences of individuals (Henwood & Pidgeon, 2003). Grounded theorists have sought understanding over seeking causative explanations, have relied on dialectical process (Bulmer, 1979), and have utilized theory as guidance, rather than for hypothesis testing (Henwood & Pidgeon, 2003). Iterative processes are emphasized whereby theories and research questions are constantly revisited as data are collected and reflected upon. Often, this results in revision of research questions, recategorization of initial codes, and reevaluation of important concepts as an investigation progresses (Henwood & Pidgeon, 2003).

Differences have emerged with regard to the extent to which this iterative process should lead researchers to utilize theoretical models in the initial conceptualization of research questions and specific methods. These differences are often exemplified by contrasting the perspectives of Glaser (1992) and Strauss and Corbin (1998). Glaser (1992) takes a strong constructivist stance, advocating little initial application of theory and only broad research questions. On the other hand, Strauss and Corbin (1998) promote an initial position more guided by prior research and existing theories. Most promoters of grounded research take this latter stance, with explicit attention to being flexible and not rigidly applying a particular theory or framework (Henwood & Pidgeon, 2003).

The current study utilizes the more flexible application of grounded theory, congruent with a pragmatic epistemological position described above. Current theories regarding developmental social cognition, brain injury, and rural health and disability directed initial questions and guided interviews. This viewpoint is described by Henwood and Pidgeon (2003) as theoretical agnosticism, rather than theoretical ignorance. By using extant theories to guide the

creation of initial questions and further probes, I adopted the theoretical standpoint endorsed by Strauss and Corbin (2008), more so than the purely constructivist notion endorsed by Glaser (1992).

Qualitative Methods with Children

Qualitative research holds much promise for understanding child psychological phenomenon. Nelson and Quintana (2005) specify several specific areas in which qualitative methods make significant contributions to clinical child and adolescent research including theory development, establishing clinical relevance, addressing cultural validity of findings, and understanding cultural context of research and practice. However, typical data collection techniques are often complicated by developmental and verbal level of the children being studied (Nelson & Quintana, 2005). They offer several suggestions for researchers; utilizing clinical skills of reflection and summary statements, offering both general and specific questions, being conversational, and being creative with child-friendly activities. McConaughy (2013) specifies several considerations for interviewing adolescents, such as using simple language, using problem-solving questions to probe cognitive maturity, placing importance on establishing rapport and respecting limits, and being prepared for emotional lability.

Present Study

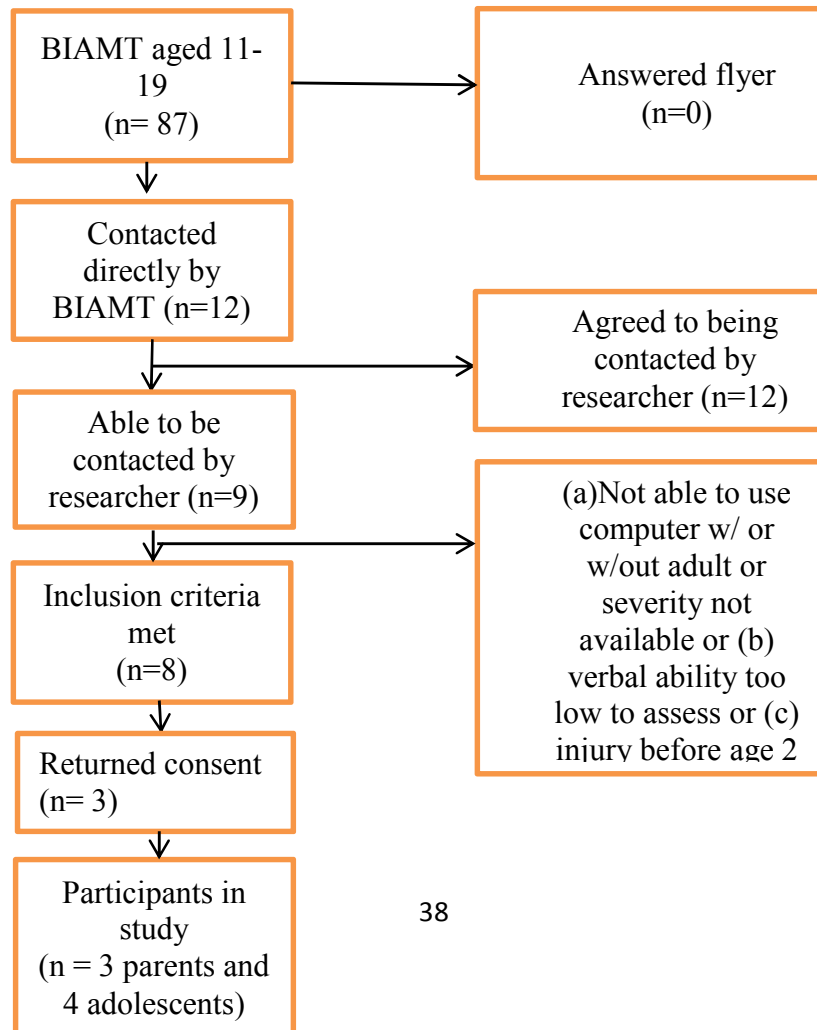
Participants

Participants were selected from the individuals who are currently in the database maintained by the Brain Injury Alliance of Montana (BIAMT). Originally, recruitment flyers were created and sent to the 87 individuals eligible by age for the study. After one month, there were no replies to the flyer. Next, a representative of the BIAMT asked twelve parents if they

and their children were interested in participating as part of routine follow-up that included telephone contact. All twelve parents agreed to participate with their children. Those names were provided to the primary investigator. Of the twelve parents, four could not be contacted and one was ineligible due to inability to use a computer. The remaining eight parents agreed to participate in the study and were mailed materials. One parent dropped out of the study prior to consent citing her child’s multiple disabilities as the reason. Parents were contacted a maximum of three times regarding completion and return of study consent and materials. Three parents (of four adolescents) completed the materials and returned them. The recruitment process and number of parents at each stage is shown in Figure 3.

Figure 3

Recruitment Funnel



The participants included adolescents and their primary caregivers (mothers in all cases). Inclusion criteria after parental consent was obtained were: (a) aged 12-18 years, (b) initial severity level estimated by using any combination of loss of consciousness, post traumatic amnesia, brain imaging, or brain scan, in accordance with Table 1, (c) subject able to interface with computer with or without assistance, (d) language ability must be high enough to assess via telehealth software, (e) the initial brain injury must have occurred after the age of two.

Table 1

TBI severity taxonomy

Severity	GCS	LOC	PTA	Other
Mild	13-15	< 15 min.	< 24 hrs	No positive imaging, skull fracture, or brain swelling
Moderate	9-12	15 min – 24 hrs	1-7 days	
Severe	< 9	> 24 hrs	> 7 days	

Note: Participants were categorized according to the most severe category of any of the symptoms for which data is obtained. GCS = Glasgow Coma Scale; LOC = Loss Of Consciousness; PTA = Post-Traumatic Amnesia.

Participants were entered into a drawing for two \$100 prizes and provided with a qualitative summary of strengths and weaknesses from the evaluation.

A summary of characteristics of each of the four adolescents is presented in Table 2.

Table 2

Participants with TBI background information.

Participant	Age at Interview	Injury	Time from Injury	Descriptive Information
Ricardo; Hispanic male	15 years 3 months; 8 th grade	8 years; 3 rd grade; mild TBI; fall from playground equipment	~7 years	Ricardo lives with his mother in a Montana town with a population of 200 that is located approximately 45 miles from a relatively large urban area on a reservation. His mother has a graduate degree and is employed. He had developmental concerns previous to his TBI, including a learning disability and developmental apraxia subsequent to reported cognitive regression at age three. Although not substantiated, this regression may have been related to a suspected head injury while in the care of his father.
Natalie; European American female	18 years 10 months; College freshman	16 years; 11 th grade; moderate TBI; car wreck	~3 years	Prior to college Natalie lived with her mother in a town in Wyoming with a population of 9500 that is located approximately 100 miles from the nearest relatively large city. Natalie's mother has a high school degree and is employed. Her injury was the most severe of the participants and

included skull fractures, brain swelling, and an MRI indicating frontal lobe damage. She also lost most of the hearing in one ear because facial bones were forced through her ear canal. She had no developmental concerns prior to the accident.

Reba;
European
American
female
16 years
11
months;
11th grade
13 years;
8th grade;
mild TBI;
ejected
from bed
of truck
~ 3
years

Reba lives with her mother, father, and her sister, Kelly (see below) in a Montana town with a population of 7000 that is twelve miles from the nearest relatively large city. Both parents have high school and some college education and are employed. She is active in church and sports and has had two to three prior concussions.

Kelly;
European
American
female
18 years
10
months;
working
16 years;
11th grade;
moderate
TBI;
ejected
from bed
of truck
~ 3
years

Kelly is Reba's sister (see above). Her injury was more severe than her sister's due to a skull fracture and hemorrhaging. Kelly lives at home with her parents and sister and is working a part-time job.

In summary, participants included one male and three females who were from small towns with varying proximity to larger suburban areas. At the time of the study, they ranged in

age from fourteen to seventeen years old. Using Table 1 criteria, two participants sustained mild TBIs and two participants sustained moderate TBIs. The three female participants sustained TBIs in adolescence, while the male participant sustained a TBI in childhood.

Experimental Materials

Several direct assessment measures, as described below, were administered via telehealth software with the adolescents. The telehealth software used is OmniJoin by Brother. OmniJoin is designed for medical video conferencing and is cloud-based, secure, and compliant with the Health Insurance Portability and Accountability Act (HIPAA) regulations. This technology, and similar telehealth technology, allows clinicians and patients to interact using a variety of tools in a shared space, including video and programs on either participant's computer. The moderator can use the shared viewing space to display either participant's desktop or run programs and applications. For example, to administer a task that required participants to watch a video and answer questions (virtual reality social problem-solving), the researcher played the video on his desktop and then used the OmniJoin shared space to allow the participant to view the video.

Quantitative Measures

Demographic questionnaire. A demographic questionnaire created by the researcher was used to collect information on family resources, living situation, and other relevant factors. The questionnaire used in this study can be found in Appendix A.

Neuropsychological functioning. Measures of neuropsychological functioning were administered using telehealth software, as described above.

Digit span. The digit span task from the *Wechsler Intelligence Scale for Children, Fourth Edition* or *Wechsler Adult Intelligence Scale, Fourth Edition* (WISC-IV or WAIS-IV; Wechsler,

2003; Wechsler, 2008) was administered and the scaled score was used. This test measures short-term memory and working memory. This task requires participants to recall numbers that are read to them at a rate of one number per second. The task has a forward and a backward component for all age groups and a sequencing component for 16 and older, or those taking the WAIS-IV. In the forward task, participants are required to recall the numbers in the order they are read, the backwards task requires that they recall the numbers in reverse order, and the sequencing requires that they restate the numbers in numerical order. The digit span subtest has demonstrated good reliability with an internal consistency of .87 to .92 depending on the age group (Wechsler, 2003b; Wechsler, 2008b). Separate forward and backward norms were used to score instead of using the combined standardized score in order to better facilitate comparison between participants of differing age groups.

Controlled Oral Word Association Test (COWAT; Benton & Hamsher, 1976). This test requires participants to name as many words that begin with a particular letter as they can in one minute. The most commonly used letters are F, A, and S. The number of unique words generated is recorded. The COWAT is a measure of the executive and semantic/generative aspects of language, is related to temporal and frontal lobe functioning (Baldo, Schwartz, Wilkins, & Dronkers, 2006), and is sensitive to TBI (Lezak, Howieson, Bigler, & Tranel, 2012). There are a number of published norms for this measure; for example, the *Delis-Kaplan Executive System* (D-KEFS; Delis, Kaplan, & Kramer, 2001) has provided scaled scores and percentile ranks for ages 8-89. For this age range, the internal consistency and test-retest reliability of the D-KEFS letter (FAS) categories fluency test are .77-.81 and .67, respectively (Delis et al., 2001).

Social Measures

Social problem solving. A virtual reality social problem-solving task (VR-SPS) was used to measure ability to identify and solve interpersonal problems. The VR-SPS is a virtual reality task adaptation of the *Interpersonal Negotiations Strategy Test* (INS; Yeates, Schultz, & Selman) adapted for use on the program Second Life (Rosedale, 2003). The INS has been tested extensively in TBI populations (e.g. Hanten et al., 2008) and the VR-SPS has been demonstrated valid for use with youth ages 12-19 with TBI (Hanten et al., 2011). Hanten and colleagues (2011) hypothesized that the VR-SPS may be more sensitive to brain impairment in adolescents than the INS, perhaps because the VR-SPS presents a more naturalistic dialog creating a more complex and realistic scenario. Like the neuropsychological tasks, the VR-SPS was administered using the telehealth software in the present study. The researcher played the video and then asked the participant questions based on the video.

The VR-SPS requires participants to watch up to six computerized scenarios involving four people, two of whom are in conflict (Hanten et al., 2011). There are two possible scenario types, one involving two youth and one involving a conflict between a youth and a parent. Within these two types of scenarios there are three conditions, increasing in the amount of extraneous conversation and number of characters involved. However, Hanten and colleagues found that their third condition demonstrated the greatest ability to detect social cognition deficits in participants with brain injuries and avoided measurement floor effects. In the current study, only the third condition, Condition C, was used. Scenarios involved child to adult conflict with another child and adult present, and an extraneous conversation. The child was gender-matched to the participant. These choices were made to be consistent with prior research on the

VR-SPS (gender matching; Hanten et al., 2011) and to minimize experiential difference that might be found when comparing adolescents who interact with many peers and those who do not.

Participants are interviewed with nine questions about the nature of the disagreement. Each of the four problem-solving steps is represented in the questions: defining the problem, generating strategies, selecting specific strategies, and evaluating outcome. Participants are scored on a four-point scale representing a developmental hierarchy: impulsive = 1, unilateral = 2, reciprocal = 3, or collaborative = 4. Hanten et al. (2011) demonstrated that inter-rater agreement was .89 to .98. The VR-SPS generates scores for each problem-solving step and a summary score.

Social functioning. Social functioning is used to describe social interaction and social adjustment. Assessment of social functioning was accomplished by rating scales which included one measure of social interaction and one of social adjustment.

Social interaction. *The Social Skills Rating System – Parent Form* (SSRS-P; Gresham & Elliott, 1990) was used to measure parent perception of their child's current broad social skills, competence, and behaviors. Parents rate their child on 40 items using a 3-point likert scale indicating if a skill is never used, sometimes used, or almost always used. This measure contains subscales measuring a variety of social skills that support effective social interaction, such as communication, cooperation, and engagement. Questions on the SSRS can be found in Appendix B. The SSRS contains a problem behaviors subscale that was not used in the current study because this study focusses on behaviors more directly related to social outcomes. This

measure yields *t*-scores normed by age (3 to 18 years) and gender. The reliability alpha coefficient is above .74 for all subscales at all ages.

Social adjustment. Participants completed the *Social Relations-Interaction with Peers-Short Form* (SR; National Institute for Neurological Disorders and Stroke, 2010). This is an 8-item scale covering perceived quality of social interactions in the previous week. Scales were developed with input from patients and professionals, literature reviews, and a multi-step reviewing process, followed by item-response-theory analysis (Jin-Shei et al., 2012). All of the pediatric neurological quality of life measures have alpha coefficients higher than .90. Scores were summed and the total raw score was converted to a *t*-score. Questions from the SR are shown in Appendix C.

Procedure

Parents of adolescents were contacted first for consent and to ensure inclusion requirements are met. If adolescents lived outside of their parents' home, adolescents were contacted to obtain consent to participate. Upon consent, parents were mailed the demographic questionnaire and the SSRS-P. Next the adolescents and young adults were contacted via computer interface on telehealth software. They were administered the VR-SPS, digit span, and COWAT, in that order. They were thanked for their participation, told that a summary would be arriving by mail, and reminded that they would be entered into a drawing. The basic interview protocol is shown in Appendix D.

All participants were then contacted again and asked to participate in the interview portion of the study. Second consent forms were sent via mail, signed, and returned. After consent to participate was obtained, participants were contacted by telephone and interviewed.

They were reminded that they were already entered into the drawing and did not have to continue participation if they so choose. Interviews lasted approximately 50 to 60 minutes for parent participants and 15-25 minutes for adolescent participants. At the end of the interviews, the SR was administered via interview. Interviews were then transcribed verbatim and entered into NVivo (version 10, QSR International) for analysis. This software was used for coding sections of text into themes. Themes were stored, defined, combined, and compared on NVivo. A log was also kept on NVivo that was used to create an ongoing commentary on decisions made regarding themes, relationships between themes, and links to supporting text for ideas and relationships. This log serves as an audit trail that enables one to chart the course of the project and how decisions were made. Keeping a log is generally considered an important transparency element in qualitative research (Bowen, 2009).

Using a method of specifying sample size criteria proposed by Francis (2010), an initial analysis sample of three caregivers and four adolescents was used, with a stopping criterion of two interviews with no new themes emerging. Following the initial sample, no new themes had emerged for the previous two participants (two adolescents who were not related); therefore, no new participants were recruited.

Qualitative Analysis

Qualitative data were analyzed and interpreted using a grounded theory framework (Glaser & Strauss, 1967). Guiding interests and concepts was a point of departure for developing ideas. A theoretical guiding framework was established and modelled in NVivo prior to conducting the initial interviews. The initial model is shown in Appendix E. Specific concepts that emerged from participant-researcher interactions were developed through successive stages

of analysis and studying data. Simultaneous analysis and collection of data lead to new questions and ideas for themes. All participants got the same line of inquiry, but because new and emerging themes were explored, additional probes and follow-up questions were added.

As previously mentioned, a log was kept to ensure transparency and to document ongoing decisions in context. This method is one way of establishing what is referred to as “trustworthiness” in qualitative research (Guba & Lincoln, 1989), although the ability of an audit trail to lend credibility to decisions has been contested (Morse, Barret, Mayan, Olson, & Spiers, 2002). The perspective of Morse et al. (2002) has been adopted in this project and criteria of reliability and validity as indicators of rigor have been retained. Reliability and validity were achieved primarily through the iterative process (Morse et al., 2002). Additionally, the methodological coherence and sampling sufficiency described earlier in this manuscript contributed to reliability and validity, as did the use of a dynamic sampling and analysis interaction (Morse et al., 2002). Other steps taken to ensure reliability and validity of the research process included triangulation of qualitative and quantitative findings (Torrance, 2012) and the use of reliability coding checks with a second rater. These methods and processes are discussed in more detail below.

Analysis procedure. Several methods were used to analyze the interviews. First, initial themes were created, and then themes underwent a refinement process using multiple strategies. Sampling and analysis occurred simultaneously, so analysis procedures were cycled through, to varying degrees, for each interview. Bryman’s (2008) four stages of qualitative analysis were used to develop initial themes and for every interview. The following stages of analysis were used for each interview that was administered:

1. Read the text as a whole, making notes and beginning to identify themes, unusual issues, and categories (may reflect research questions).
2. Read the text again, marking the text and making notes, labels, key words, and analytic ideas.
3. Code the text, systematically marking the text and reviewing codes, combining and grouping codes.
4. Relate general theoretical ideas to the text, interconnections between codes, and relation of codes to the research questions and literature.

To aid in the creation of a clear and reliable coding scheme, consistency checks were used to check on the clarity of categories. Consistent with a process described by Thomas (2006), a second coder was given the objectives, categories, and descriptions of the categories along with samples of the raw text. The second coder assigned sections of the text to the categories previously developed. Discrepancies between the two raters were used to refine themes and operational definitions. As a result of this process, several themes were combined and some themes were found to fit better as subthemes within other themes. More text was coded with the new themes, and then the process was repeated three more times, until 100% agreement was reached. This process resulted in a final reduction to five major themes with twenty-four subthemes.

Themes were organized and analyzed in NVivo using several methods. First, a visual model with all the themes was created. Themes were physically sorted into groups of conceptually similar themes. Then, a theme query was used to allow the viewing of the text that is coded in several themes that had been grouped together due to their perceived similarity.

When viewing all text, new nodes were combined under different themes. This process was used for several groups of related themes. For example, two subthemes relating to the adolescents' perception of the way peers view the adolescent's injury related changes (physical and behavioral) were originally grouped under Ability Change. They were very similar conceptually to Teasing and Stigma, which was a subtheme of Friends Change. When text from all three themes was viewed using a node query, all three subthemes were grouped together as Peer Reaction. Then, Friends Change was made a subtheme of Peer Reaction.

Using the visual modelling process, themes were naturally grouped together and relationships were noted. New nodes were created that encompassed groups of themes and could be more easily used to depict relationships between groups of themes. These new, organizing nodes allowed for a better defined hierarchical structuring of themes.

A table displaying each theme, and details regarding the text categorized under that theme, was also used to sort and group. The number of sources (individual's interviews) and the number of references (total number of text segments) filed under each theme was analyzed. Themes with few sources and references were reanalyzed to determine if they fit under an existing theme, or if the creation of a new theme could encompass the rarely used theme with other existing themes.

Quantitative Analysis

Quantitative results were integrated into qualitative findings at the interpretation stage of the study. Quantitative data were derived from the questionnaire and rating scales, direct assessment measures, and environmental factors (e.g. geographic location). These data were used

to supplement, explain, and enhance emergent themes and connections and to support themes and interpretations.

CHAPTER 4

RESULTS

Quantitative Findings

Results of direct assessment and rating scales indicate that the adolescents demonstrated a range of abilities. Ricardo demonstrated some impairment in social skills and social quality of life and clear impairment on the measures of short-term and working memory. Verbal fluency and social problem-solving were close to what would be expected for someone his age. Reba and Kelly demonstrated some difficulty with the more complex short-term memory/working memory measure, and Reba demonstrated difficulty with the verbal fluency measure and in social problem-solving. Both girls' scores in social skills and social quality of life were average to above average as compared to female peers. Natalie scored in the average or above average range on all measures. Table 3 displays results of quantitative findings.

Table 3

Scores from Direct Assessment and Rating Scales

	Ricardo	Reba	Kelly	Natalie
Digit Span				
Forward (sc)	2	9	8	12
Backward (sc)	2	4	6	12
COWAT (sc)	8	6	9	15
VR-SPS (means) ^a				
Defining Problem (rs)	2.0	2.3	3.0	3.0
Generating Strategies (rs)	3.0	2.0	4.0	3.0
Selecting Strategies (rs)	3.0	3.0	3.0	4.0
Evaluating Outcomes (rs)	2.5	2.0	3.0	3.5
SSRS				
Cooperation ^b	Fewer	More	Average	More
Assertion ^b	Fewer	More	More	More
Responsibility ^b	Average	More	Average	More
Self-control ^b	Average	More	Average	More
Total (ss)	81	130	120	130
SR (ts)	34.2	54	59	56

Note. sc = scaled score (mean = 10, standard deviation = 3) ss = standard score (mean = 100, standard deviation = 15); rs = raw score; ts = *t*-score (mean = 50, standard deviation = 10); COWAT = Controlled Oral Word Association Test; VR-SPS = Virtual Reality Social Problem-Solving Test; SSRS = Social Skills Rating System; SR = Social Relations – Interaction with Peers, Pediatric Form.

^aVR-SPS mean scores by problem-solving stage are reported. The numbers correspond to judgements of response quality: 1 = Impulsive (physical only); 2 = Unilateral (one-sided); 3 = Reciprocal (two-sided); 4 = Collaborative (mutual goals/long-term effects).

^bSSRS ratings summarize social skills as Fewer (than average), Average, or More (than average).

The quantitative measurement only marginally describes each participant in their unique and rich variation. Therefore, quantitative results are interpreted in respect to qualitative theme results for each participant in the section below.

Qualitative Themes

Qualitative analysis of interviews resulted in the identification of 23 themes. The themes were then organized under larger umbrella themes. The 23 originally identified themes became sub-themes for the organizing umbrella themes. The organizing umbrella themes and their definitions are shown in Table 4.

Table 4

Organizing Umbrella Themes and their Definitions

Assessment Method	Statements and answers to questions regarding the methods used for assessment.
Personal Change	Intrapersonal changes as a direct result of the TBI
Environmental Response	Automatic or difficult to control responses of the child's and family's environment, including people and organizations.
Social Needs	Met or unmet expressed needs; Also conceptualized as "Intentional Changes" that are made or desired to lead to better social abilities or opportunities. Need categories are not mutually exclusive.
Facilitators and Inhibitors of Intentional Change (FIICs)	References to factors that made desired environmental changes easier or more difficult to obtain, including geographic, personal, and professional factors.

Four themes, specifically, Personal Change, Environmental Response, Social Needs, and FIICs, are highly interrelated and conceptualized as representations of change processes. In contrast, Assessment Method is a theme that is related to the measurement of the change processes described by the other themes. While it remains highly related to the other themes, assessment themes have less reciprocal influence on other emergent themes. Furthermore, Assessment Methods is largely a class of responses to specific probes, rather than organic themes derived from text. That is, much of the compositions of the themes are interview questions with yes/no responses. Therefore, further analysis and interpretation of Assessment Method will be

conducted separately from the other themes. The remaining four themes can best be conceptualized in an interactive framework.

Assessment Methods

Mailed packets of consents and initial surveys took between two weeks and two months to be returned. Because the researchers required that the packets be returned before proceeding to the next stage of the study (the consent form was included in the packet), a failure to return the packet resulted in attrition from the study. Five of the eight parents who received the packets failed to return them. A maximum of three to four follow-up calls were made to each parent. Once packets were received there was no further attrition. This difference in attrition has implications for research and clinical practice when considering the use of mail or electronic communication as elements of a study or assessment battery. These implications are discussed further in the discussion section.

During the interview, all participants responded that they felt the rating scales and questionnaires were convenient and not overly time consuming. The only issue raised with regard to these methods was an issue of the degree to which problems arose from TBI. Natalie's mother reported,

Certain things were hard to assess. In [Natalie]'s accident, she also lost the hearing in one of her ears. I think it's hard to determine what part of some things was hearing loss and what parts of it are brain injury.

One parent commented that the interview portion of the assessment was important to her because rating scales and questionnaires felt limiting.

Assessment with adolescents was done primarily through telehealth software. In respect to the research question, "is remote assessment feasible", it is important to note that not one person contacted for this study reported a lack of internet in their home. One participant did not have a webcam in the home. The family was mailed a webcam to use and reported no difficulty setting it up and using it. Details regarding the technology used by participants were not gathered; however, all participants reported that they experienced no difficulty installing software, logging on, or otherwise participating in the computerized portion of the assessment. No difficulties were experienced during the administration of the assessment, although at times there was a slight lag time between video and audio. Such a lag did not affect the one timed measure used (COWAT), but has the potential to affect measures of reaction time or processing speed that rely more heavily on small units of time. One family had inconsistent cellular service in their home, so sometimes their landline was used, and the cellular phone was used at other times. This made contacting them slightly more difficult.

All participants reported that they were satisfied with the ease and convenience of the computerized portion of the assessment. In response to a question about thoroughness of the data collection, one participant responded that I may benefit by including a measure of processing speed, because she has had trouble with processing speed. All participants agreed on the ease of participating in the study. Multiple adolescents reported that the assessment was hard at times, but they seemed to conclude that difficulty was desirable and indicated that abilities related to brain injury were being assessed. For example, Natalie commented that the assessment required that she "focus on concentrating and remembering and stuff that could be affected by a brain

injury.” One participant, Reba, reported having a headache at the time of assessment. When asked if the assessment made her headache worse, she replied that it did not.

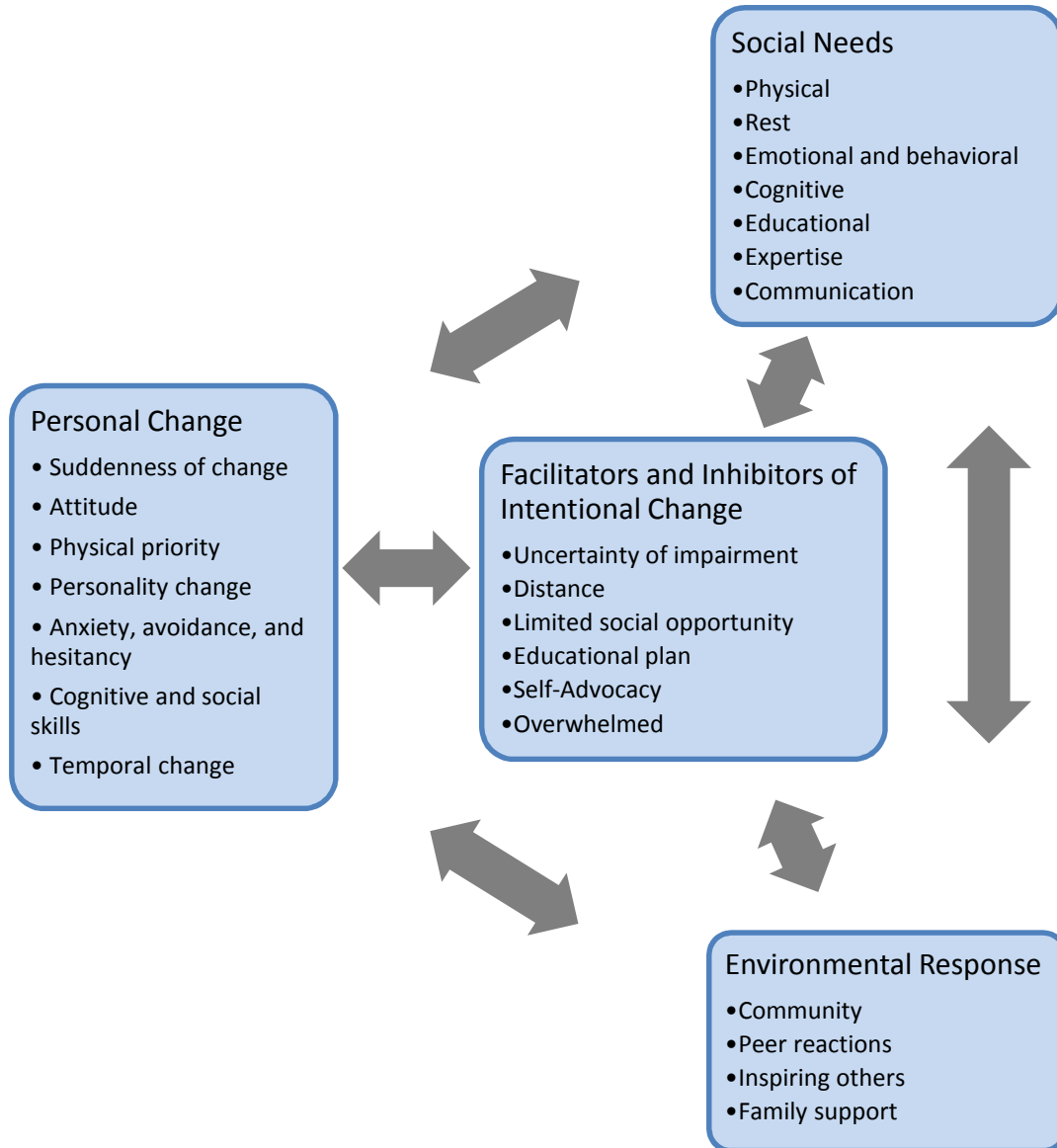
Overall, assessment methods were judged by participants to be convenient, valid, non-intrusive, and comprehensive. Problems with returned packets, and thus attrition, were present with the mailed packets, but no such concerns were present with the electronic portion of the assessment.

Change Themes

Emergent and organizing themes related to change, specifically, Personal Change, Environmental Response, Social Needs, and Facilitators and Inhibitors of Intentional Changes (FIICs), are shown in Figure 4.

Figure 4

Change Themes and their Interrelationships



In this model, the four organizing themes are presented along with their subthemes and arrows depicting their interactions. Personal changes are the direct result of the brain injury.

Likewise, Environmental Response encompasses more automatic responses, or responses over

which the family has little initial control. Conversely, Social Needs are intentional, or desired, environmental adaptations. Facilitators and Inhibitors of Change represent actions toward changing the environment in the desired fashion and barriers to doing so.

Themes are not mutually exclusive and can best be conceptualized as distinct, but highly related. Immediate changes as a result of the TBI determine desired response. The desired change is accomplished through mediating variables. For example, frequent headaches lead to a desire to have a shortened school day. If the school allows for a shortened school day, the shortened day is the educational plan that is the mediating variable facilitating desired environmental adaptation.

Personal change. Suddenness of change and attitude regarding change are two interrelated concepts that occurred in the interviews. They represent emotional reactions and cognitive interpretations of the events surrounding the adolescent's TBI and the ensuing changes.

Suddenness of change. Suddenness of change was not expressed by many study participants, nor was it expressed many times throughout interviews. However, when it was expressed, it seemed to have particular poignancy for the interviewee (both of whom were parents). For example, Ricardo's mother's voice trembled slightly when she reported that, "It is bothersome to fall off of something and then waking up and they don't do what they used to." At the conclusion of her interview, Natalie's mother made a point of expressing her concern for other families around this issue by saying, "Nobody ever expects to have to go through a situation like this... my daughter had asked to stay the night with a friend, it was just a night like any before and I had some bills that were overdue and none of that mattered Saturday morning."

Attitude. The attitude theme captures both positive and negative interpretations of the unfolding of injury-related sequelae. The vast majority of text coded in the attitude subtheme was of a positive nature. Belief in ability, either through belief in one's self or in belief in a greater power or purpose, was expressed by several participants. Natalie stated,

The most helpful thing was probably just believing in myself because if I didn't believe in myself then I didn't really have anyone who did, and if I didn't believe I could do it then I wouldn't be able to do it. And so just pushing myself and not focusing on what was wrong with me, but what I still had. That was really helping me.

Similarly, her mother said of Natalie,

When [Natalie] first got hurt I braided her hair, she was a warrior and I guess that the medieval women would braid their hair when they went into battle so even if she did have a brain injury, it didn't matter. Even if, she was still going to have to work hard no matter what. It didn't matter, we didn't just sit there wonder if she was going to be able to do this, we did what was in front of us.

Accordingly, Natalie demonstrated exceptional cognitive and social abilities on assessments.

Reba and Kelly's mother expressed a change in the manner in which her family appreciated daily life. She said, "After it happened, we got a book, every night we would write our blessing in for the day." When Natalie was asked about changes in her satisfaction from peer interaction, she replied, "Yes, I appreciate them a lot more," and went on to explain that, "I realize how fast life can be taken away." Reba, on the other hand, expressed her handling of her peers' negative reaction to her social difficulties with indifference, stating that even though it bothered her sometimes "it just is what it is."

Physical priority. Several changes in physical, mental, and personality characteristics were discussed by adolescents and parents. It was clear that all of these changes affected socialization and social process a great deal. Interestingly, but unsurprisingly, a need to attend to physical concerns and to be mindful of physical limitations was often a salient theme, especially with regard to the first year after the injuries. Adolescents struggled with headaches, food and light sensitivities, and balance problems. Often, these issues compromised their participation in activities such as school and sports. Years after the accidents, all participants continue to miss school and work due to headaches or because they have to travel long distances to go to medical specialists.

Personality change. Personality change was described in several ways. Natalie's mother said that "She is a lot more spontaneous and she fully knows the consequences of something and what is riding on it and have every intention of not doing it and then it's like she just forgets," elaborating that she is "dumfounded" by Natalie's choices at times. Natalie scored well on all of the cognitive and social measures administered, and on questions regarding Natalie's number of friends and if her number of friends changed, Natalie's mother indicated the greatest amount (>8) both before and after Natalie's TBI. However, both Natalie and her mother describe changes in the friends with whom Natalie chose to spend time. Natalie's mother stated,

Well, I know that before she was in the accident that she typically hung out with the people that would be considered...I'd say the nerds or the preppies, you know? People that were working hard for a future...But I noticed that the kid that were starting to come over were the one who had rough lives at home that were the dropouts, that were struggling, that were making bad choices, that were on probation.

Natalie's mother expressed her concern that Natalie was not as motivated toward future goals as she had been. She described Natalie's new friends as "stoners" and cited an example in which Natalie brought marijuana on a school trip, jeopardizing her future. Natalie described the change in friends in terms of her peers' reaction to her injury. She stated that she "found out who her real friends were," because they were the kids that continued to visit her after her initial recovery.

Ricardo also expressed changes in his personality and emotional reactivity. Both Ricardo and his mother described anxiety as a barrier to social interaction, but Ricardo also expresses a change more generally related to personality change or emotional reaction. Ricardo described himself as "more sensitive" now in relation to friends not wanting to spend time with him anymore.

Anxiety, avoidance, and hesitancy. Anxiety, Avoidance, and Hesitancy are internal states resulting from the TBI and surrounding events (e.g. accident) that result in deterring the adolescent from engaging in social behaviors. This reticence is described in several ways. Some participants described distinct and exaggerated fears of particular situations related to the accident. Natalie's mother said, "For a while she didn't hang out with anybody because she didn't want to get in a car. I was the only one that she would let drive her anywhere." This statement captures the social implications of fear and hesitancy. Later in the interview, she described the severity of post-traumatic symptoms while discussing an accident that Natalie's brother had been in two years after Natalie's accident, saying that "because of what she had been through during this accident it made her relive the whole thing." Ricardo describes a more generalized anxiety, when asked about what his needs were after his accident he stated, "That was when I got so nervous." When asked what he was nervous about, he replied "Everything," and went on to

describe routine interactions with peers. Kelly described her reluctance to talk about the accident with her peers and how she would “tell them the gist of the story” to appease them and avoid going into details.

Cognitive and social skills. Several of the participants described changes in social skills and cognition. Reba and her mother described Reba’s changes in ability to process information and her slowed speed of processing. Both participants discussed the difficulty Reba experienced, and continues to experience with following conversations. Relatedly, Ricardo’s mother described Ricardo’s difficulty with social interaction, saying that he struggles to find something to talk to other kids about, “and then, if it turns out that this is not what the kids want to talk about, well, then I don’t know what to do after that.” Assessment results are consistent with quantifiable impairment in social, linguistic, and cognitive abilities, but did not capture the reciprocal interaction that these impairments may have with the emotional changes Ricardo and his mother describe. Ricardo relates his social experiences back to his emotional reaction, “I try my best and they don’t really care, and I feel left out, like always I feel left out.” Ricardo was the only participant whose assessment data indicates a loss of friends following the TBI. His mother indicated on the questionnaire that Ricardo currently has no friends.

Temporal change. Most changes to the adolescents were described as changing significantly over time. Specifically, most often, symptoms were described as completely remediated or significantly improving over time. However, some symptoms remained, perhaps at a lower level, as was often the case with headaches and memory problems, while others remained the same or worsened. Social difficulties were described as worsening over time by Ricardo and his mother, who both describe his difficulties in the context of a dynamic social

landscape with limited peer options. Ricardo's mother reported clearly worsening social abilities following his TBI in third grade, saying "I could see him struggling in 4th grade, and when he hit 5th and 6th grade it was more obvious, and then being social was harder for him, and 7th and 8th grade was terrible." Ricardo expressed that he definitely believes his friendships changed following his TBI. He described more succinctly his experience of the difficulty he has had adapting to a changing social milieu, "Everybody else is changed. But I don't really remember when and how." Kelly and Reba's mother described how the treatment of her daughters has changed even though many of the changes experienced by the girls remain, such as headaches and slow processing. She stated that Reba's basketball coach no longer acknowledges the TBI despite the fact that Reba has a harder time with the pace of the game than she used to. She also described how Reba's headaches no longer get much attention at home and that her school often does not take into consideration needs Reba may have as a result of her TBI. This lack of recognition of impairment due to TBI is in the context of reports by Reba and her mother that Reba continues to struggle with speed of processing and verbal comprehension. Additionally, results of this study clearly indicate potential impairment in short-term/working memory, the executive component of language, and social problem-solving.

Environmental response. A variety of automatic processes and reactions were described by participants. Environmental entities include the family, peers, and the community. Responses encompassing environmental response were dominated by mentions of peer and community reactions to the TBI.

Peer and community responses. Peer and community responses appeared directly linked to the visibility of the accident to the community. For example, Natalie's car accident involved

several other peers, and occurred in or near town, on a weekend night, as a movie got out. While describing the accident, Natalie's mother reported, "There were members of our community that I've never even met that came to me and they said they were going to do a benefit for these kids. They knew it could be their child." Natalie's mother captured the interaction between the visibility of the accident, the small size of the community, and the dramatic interaction present in this statement when she described Natalie's reentry into school following the accident.

It was also the size of our community because there were four children in that car and they went in holding hands, I believe. I think her and the girl that was driving the car...the girl that was driving the car had her leg shattered, they actually went in holding hands. That was a sign to the community that it wasn't about blame, it wasn't about any of that other than "Thank God" were all still alive, because a few months before that, they lost a young man at the high school in a car wreck and it was a big football player that had a full-ride scholarship and all that stuff. These delicate girls were alive and it was a healing for the whole community.

In contrast, Ricardo's accident was not high profile. In fact, the school he was attending initially denied that it occurred. Neither Ricardo nor his mother described any community response to his injury. They do describe peer responses, primarily in a negative manner. Ricardo stated that peers treat him like "the slow kid," and his mother stated that "when he can't speak clearly or when his interests are different, they call him names." In contrast, Reba described peer reactions in relation to her cognitive processing changes, saying that her friends frequently commented on these challenges, "they would have to explain it to me again, oh, we have to explain it again to [Reba]."

Reba and Kelly's mother described a particular sub-community when referencing their relationship with members of their church, frequently referring to them as their "church family." Reba and Kelly's accident was also well known in the community and the family received a great deal of support following the accident from members of their church. Both Kelly and her mother discuss differing responses between people at church and those at school. When asked if her daughters experienced marginalization due to changes in cognitive and social abilities at church like they did at school, Reba and Kelly's mother stated, "I just think it was stronger, all that was different was just a stronger support system. We already have a strong support system from the church, but it was even stronger."

Inspiring others. Natalie's mother described several ways in which the community and peers reacted to Natalie's accident in a particular manner consistent with drawing inspiration from the event. For example, in describing Natalie's school reentry she stated,

Girls were crying, and not because they were like, "look at her she's a freak," they were like, "Oh my God, she's beautiful, she's missing her teeth." People were coming up to her and telling her that it made them feel like whatever they had going on was nothing. They were like, "You give me hope, you give me strength."

Although Natalie's mother was the only participant who described this particular manner of community response, she made several references to it.

Family. Reba, Kelly, and their mother's description of their "church family" blur the line between community and family. Four of the seven participants in this study make specific mention of family members in the context of recovery and reintegration. This took the form of same-aged relatives being available for social support and practice and parents being present and

patient in the helping process. Ricardo's mother described the role Ricardo's cousin (who is two years younger than Ricardo) plays in facilitating social development, "[Ricardo] is trying to be bossy and the older [his cousin] gets you know he is not as gullible and he stands up for himself so, I see it as kind of good because it gives him more experience of being around kids."

Social needs. Social processes occur in nearly all contexts and affect nearly all an individual's interactions with his or her environment; because of this, social needs were described by participants very broadly. Social needs included the ability to participate and be successful in typical social environments, such as school, work, and sports. They also encompassed having physical, emotional, and motivational needs met.

Physical needs and rest. Unlike the priority afforded to physical aspects of the Personal Change subthemes, physical needs were not frequently discussed as a need subsequent to the initial recovery process. Participants did discuss ongoing medical care doctor's visits, but did not indicate social impact of many of those needs. They did discuss rest and lowered energy as a need that had to be met, especially early in the recovery process. This need often impacted their participation in school, sports, and other activities.

Emotional and behavioral. Only Ricardo and his mother discussed the desire to change in behavioral and emotional functioning. Emotional reactivity, anxiety, social interaction were described as areas of need that had been inadequately addressed. Indeed, Ricardo's assessment data indicate potential deficits in social cooperation, self-assertion, and social problem-solving. His self-reported social quality of life is poor. For Ricardo, anxiety and poor social ability has led to increased reclusiveness. His mother stated that even if options to address these needs were

readily available, she would have a difficult time getting Ricardo to attend groups or therapy, saying, “Maybe a few years ago it might have been different, how he is now, it is hard.”

Cognitive. Several other participants described cognitive needs, including the need for multiple explanations and repeating things to cope with changes in memory and processing, and attempts to explicitly improve memory and cognition. Often, these were expressed in terms of their needs in the course of social interaction, such as when friends had to repeat themselves multiple times.

Educational. Educational needs were by far the most frequent needs discussed. Educational needs often encompassed other needs. Cognitive and social deficits were discussed in terms of educational needs, as well as physical needs (e.g., occupational therapy, note taking assistance, and minimizing headache inducing activities), speech-language, and needs for rest in the educational environment. The educational institutions were the provider of many of the services and accommodations adolescents received and most of the educational needs mentioned by adolescents and parents were met by the schools, although parents did describe difficulty getting needs met and formalizing plans. Sometimes, supports were altered prematurely by parent standards. Ricardo’s mother described her frustration with Ricardo being exited from speech and occupational therapy services “because he made progress,” and Reba’s mother stated that she would “have to remind the teacher, if she seems to be struggling in school, this could be why.”

Expertise. Some unmet educational needs were described in terms of lack of expertise. Ricardo’s mother expressed her experience of moving to another town with Ricardo, saying, “Of course the school doesn’t know how to work with him. I had him in a school that he was doing

really well in, but then we moved.” She expressed the importance of having a teacher that understood brain injury and Ricardo’s needs, but was frustrated by the lack of options in her small town in which grades get combined, so children have the same teacher for two years. She reported that one teacher “understood because she herself had a head injury. She was in a bad car accident where she lost her speech. So she knew to teach him how to use his tongue.” Whereas, “the other teachers thought he was lazy and thought he was doing [poorly in school] on purpose.”

Parents’ desire for needed expertise was expressed in relation to education, but also in other ways. Kelly and Reba’s mother explained how helpful a statewide nonprofit was in helping them understand brain injury, resources, and sequelae. She said,

They called me and sent me some information on what I could do, different things I could do for the kids through the school district, they were the ones who were helpful in me knowing I could make the school do a 504 plan and gave me the tools to know what to do within the school district to make the school district comply with what my kids needed. She also described a hospital liaison that helped coordinate services immediately upon her daughters’ discharge from the hospital. Ricardo’s mother described a similar experience she had with a neurologist Ricardo saw, saying that,

[The neurologist] has been the most informational. I think he is the one who is the most, the one who tried to explain stuff. And he was the one who was more proactive that we get him to school, you know that he can rebound and all the things that he lost and relearn.

However, parents also described difficulties with school expertise, Reba and Kelly's mother stated that, "The school didn't know much, so I even had the nurse, the school nurse in there, and she probably knew more than most other people, but the teachers hadn't experienced someone with a brain injury like that before." Natalie's mother, however, expressed a lack of knowledge and information as both statewide and local, reporting,

I felt like Wyoming, in general, doesn't have the knowledge to be able to really help with brain injuries. I mean, it just doesn't feel like there's a lot of things out there. At first the school liaison was saying just "We're going to break this down, don't be worried, don't get overwhelmed" if she chooses that you know, and then all of a sudden she started dumping so much that it was overwhelming [Natalie] and then she was like, "Well, you just need to drop that class then."

Here she expresses the lack of informational infrastructure and training, and how it impacted them locally. She also expressed frustration with the educational services and with communication between the family and the school.

Communication. The need and importance of communication between the family providers as well as communication amongst professionals is clearly expressed in various discussions on school and hospital liaisons. Natalie's mother's frustration with the liaison was related to her ability to facilitate communication between the home and school, but also likely would have been improved by increased communication with other individuals providing care for Natalie. Kelly and Reba's mother described positive experiences with the BIAMT and a hospital liaison connecting them with services.

Participants also expressed an absence of people to ask questions about brain injury and when they did have a knowledgeable person to ask, a feeling of not being listened to when expressing concerns. Ricardo's mother said that "it is difficult, difficult and frustrating when the doctors don't listen to you." Moreover, multiple participants expressed their confusion regarding manifestation of symptoms developmentally, stating that they did not have a medical professional with whom to discuss their concerns.

On occasion some cooperation between professionals was reported. For example, Kelly and Reba's mother reported that a professional that gave them "brain training" went to some meetings at the school with them. However, more often, parents did not report that professionals communicated regarding issues related to the TBI subsequent to the initial reintegration into school.

Facilitators and inhibitors of intentional change. Several emergent themes described pathways between a past or present environmental condition and desired condition. These themes either described facilitators of change in the desired direction, or barriers to achieving that change.

Uncertainty of impairment. Related to the availability of expertise, expressed in the Social Needs theme, is the difficulty several participants expressed in knowing what difficulties to attribute to the TBI. For example, when discussing Natalie's poor decision making, her mother stated that "sometimes I don't know what she needed if she is just a typical teenager or if it is the brain injury." When asked about school performance, Reba said, "I don't know if it is a result of the brain injury or just normal learning skills in school, but I don't know."

Distance. These concerns are clearly related to the previously discussed Social Need of expertise, and expertise is more difficult to obtain in rural areas. All participants reported that they do not travel far to their doctors, but some did travel far to receive specialty services. For example, Natalie's mother also reported that she had a difficult time sorting out the cause of Natalie's initial balance problems due to the fact that she also had hearing loss from the accident. Natalie's does see a hearing specialist, but she travels over 400 miles to those appointments. Likewise, the helpful neurologist that Ricardo's mother reported was one of few people that helped them understand his disability was located over 150 miles from their home town. Ricardo's mother also described travelling for mental health supports, and stated that she would be willing to travel for high quality educational supports (if they were available) or groups and activities that Ricardo would participate in (but she does not identify any).

Limited social opportunities. Ricardo's mother expressed her willingness to travel, partially as a result of Ricardo's limited opportunities to socialize with peers. Ricardo's school has combined grades and between 7th and 8th grades, there are eight other kids in Ricardo's class. Ricardo and his mother expressed the difficulty that Ricardo has in finding peers with similar interests. His mother reported that his options for peers are "extremely limited and some of them are more interested in doing bad things. That does kind of make him feel more alienated." However, Ricardo's opportunities are further limited by his anxiety and withdrawal. His mother reported that she may be able to find groups or activities in the larger city (approximately 45 minute drive), but she does not feel like Ricardo would willingly participate.

Educational plan. As previously discussed, communication between professionals working with adolescents was described as poor overall, including communication between

medical providers and the schools. Despite the lack of communication, all adolescents received some type of academic modification or accommodations. Some accommodations that were made included shortened school day, schedule changes, and note taking assistance. Ricardo was the only one in the study who had an Individualized Education Program (IEP), but he had that prior to the TBI that occurred when he was in third grade, and his classification is for a learning disability, not TBI. He reported that he did work on social and emotional regulation with his special educator, and his mother reported that his IEP feels social goals are important for Ricardo. Only Kelly had a formalized written plan in accordance with Section 504 of the Rehabilitation Act (504 plan). Interestingly, Kelly and Reba's mother reported that both girls received accommodations, but only Kelly had them formalized in a 504 plan. She stated that Reba's teachers told her not to worry about a 504 plan; they would just implement whatever accommodation Reba needed. She describes the long-term consequences of the different approaches here:

I think that now, I think the teacher, well the teachers at the high school for my oldest, since she had the 504 plan, that was brought to the front of each of the teachers attention at the beginning of each school year, and then in the middle, when the classes go to change again if they have new teachers, it is brought to their attention. So the teachers would still touch base with them, and say "oh what is happening is this material getting too hard?" So the teachers would continually touch base. My second is a junior right now, and since she didn't have a 504 plan, we would have to remind the teacher "oh ok, if she seems to be struggling in something, this could be why."

Notably, Reba demonstrated areas of significant cognitive and social impairment on the measures administered in this study.

Self-Advocacy. Many changes were brought about by advocacy on the part of both the adolescents and their parents. Kelly and Reba's mother met many times with their teachers and administrators to determine what their needs were and how they could best be helped. Reba described a scenario in which she had to either tell teachers that she needed more assistance or rely on teachers to notice. These interactions took place in front of the whole class and during normal instruction. This dilemma is captured in this part of the interview

Interviewer: How did people meet that need?

Reba: Well I just had to say something I guess. Like I had to ask them to explain more

Interviewer: So that was something you would do a lot?

Reba: Yeah, or they just figured out that I wasn't understanding

Interviewer: ...and was that hard for you to say something?

Reba: Yea, it was

Interviewer: Why?

Reba: I didn't want to annoy them with my asking them if they could explain more.

Overwhelmed. Participants expressed being overwhelmed in many ways. Academic tasks were sometimes difficult to manage for adolescents. This experience was expressed by Natalie's mother who stated that Natalie's school liaison had her do too much work too soon. Often, however, some care was taken to manage school reentry following TBI. Natalie's mother also described being overwhelmed with Natalie's release home from the hospital, saying, "We

thought that most she will be in nursing home type of facility for a little bit...we didn't even have time to set anything up...we were trying to wade through the paperwork that we had.”

Attribute Comparisons

The responses of adolescents and their parents were compared using a matrix coding query in NVivo. The number of coded segments of text for each theme and subtheme were compared according to generation. Examining unique and overlapping contributions of adolescent and parent responses enables triangulation of responses as well as the ability to determine how responses of the two generations of participants contributed to the overall model. The results of the query are shown in Table 5.

Table 5

Node Matrix Showing Number and Percentages of Coded Text by Generation

	Parent Text Segments	Percent Parent Subthemes	Percent Parent Themes	Child Text Segments	Percent Child Subthemes	Percent Child Themes
Personal Change			31%			33%
Anxiety, avoidance, and hesitancy	3	2%		3	4%	
Attitude	13	7%		4	5%	
Cognitive and Social Skills Change	7	4%		5	6%	
Personality change	9	5%		1	1%	
Physical Priority	15	9%		4	5%	
Suddenness of change	4	2%		0	0%	
Temporal Change	4	2%		9	11%	
Environmental Response			19%			26%
Community	14	8%		5	6%	
Family support	4	2%		2	3%	
Inspiring others	3	2%		0	0%	
Peer Reactions	10	6%		8	10%	
Friends_Change	3	2%		6	8%	
Needs			30%	0		34%
Need_cognitive	1	1%		6	8%	
Need_communication	8	5%		0	0%	
Need_educational	17	10%		13	16%	
Need_emotional and behavioral	5	3%		1	1%	
Need_expertise	16	9%		1	1%	
Need_Physical	3	2%		1	1%	
Need_rest	2	1%		5	6%	
Facilitators and Inhibitors of Intentional Change			19%			8%
Distance	9	5%		0	0%	
Education_Plan	11	6%		3	4%	
Limited social opportunities	4	2%		1	1%	
Overwhelmed	4	2%		0	0%	
Self-advocacy	3	2%		1	1%	
Uncertainty of Impairment	3	2%		1	1%	

The table shows the number of text segments that were coded for parents and for adolescents, by theme and subtheme. Because interviews with parents were longer, and more sections of text were coded into themes, a percent of coded segments metric was calculated for each theme and subtheme. When interpreting the table, consideration must be given to the

interactive nature of the interviews; some differences may have resulted from differences in examiner questions, and examiner questions were influenced by participant responses. It also must be noted that some text segments were categorized in multiple subthemes and text segments were of varying length and depth.

In terms of organizing themes, participant groups appear similar, with the exception of parents discussing FIICs more than adolescents. Looking at subthemes, more differences are evident. In Personal Change, adolescents had a larger percentage of comments that discussed changes over time, such as then-and-now statements. The tendency to talk about change may also be reflected in their relatively larger percentage of coded text discussing changes in their friendships than the parent group.

Both groups had the largest percentage of coded text under the subtheme of educational needs. This is not surprising considering the amount of time adolescents spend engaged in school-related activities. Adolescents tended to explain why they had educational needs, (e.g. they got headaches, had low energy, or were bothered by the lights); although, they also frequently mentioned needs in the context of describing how those needs were met (e.g. taking breaks and note taking assistance). Parents tended to describe more unmet needs, such as lack of a written plan and lack of academic progress, and the school's lack of knowledge regarding addressing needs of a student with TBI.

Adolescents did not tend to talk about FIICs as much as their parents. When they did mention FIICs, it was usually when discussing meeting academic needs. Parents, on the other hand, discussed FIICs much more broadly, with a fair number of mentions of distance as an inhibitor of acquiring desired services or as a barrier to progress.

In general, adolescents made a high percentage of their comments on their cognitive and social changes, their difficulties in school and what was done that helped them, how their symptoms changed over time, and how their friends reacted to them and changed. Parents tended to have more coded text reflecting a broader perspective that more explicitly incorporated context, including the role of a positive attitude, the need for more expertise, geographic difficulties encountered, and the roles and reactions of the larger community.

CHAPTER 5

DISCUSSION

Summary of Findings

Emergent Model

This study explored processes broadly related to socialization for a small sample of rural adolescents with TBI and their families. Employing a primarily qualitative methodology allowed me to explore this topic from the perspective of the adolescents and families involved, including in-depth probing of the perspective of the adolescents themselves. To the best of my knowledge, this is the first study to explore social change processes from the perspective of adolescents with TBI. Furthermore, this study employed selected quantitative measures for the purposes of triangulation. The measures used for this study included traditionally used instruments as well as experimental measures and were selected based on contemporary TBI and social impact paradigms. An exploratory dimension to assessment was investigated by using telehealth software to administer cognitive functioning measures remotely.

A model of social change processes emerged from this study; the model consisted of four interactive categories of subthemes: Personal Change, Environmental Response, and Social Needs. A fifth subtheme, Assessment, was created largely from responses to specific probes rather than organically derived from interview text. None of the themes are mutually exclusive and sections of text often express multiple themes. Two themes, Personal Change and Environmental Response, describe automatic or semiautomatic changes that occur immediately following the injury. One theme, Social Needs was used to describe intentional or desired environmental changes. Finally, a theme of Facilitators and Inhibitors of Change (FIICs) was

used to capture actions toward changing the environment in the desired fashion and barriers to doing so. In this model, assessment methods are best viewed as a way of assessing changes, prioritizing future changes (needs), and selecting facilitators and inhibitors as targets of intervention.

Unique in its emergence from the lived experience of rural adolescents with TBIs and their families, this model provides a means of conceptualizing change process following pediatric TBI, especially related to social processes. It may also provide a framework to practitioners and educators who work with families affected by TBI in assessment and intervention.

Implications of Findings

Social Needs

Despite mild to moderate TBIs and moderate to high functioning in the sample overall, disruption to social processes were reported for all participants. Furthermore, all participants remain affected by these disruptions several years later. On the mild end, Natalie's friend group changed rapidly following her accident; however, Natalie reported very high satisfaction with the social quality of her life. On the more severe end, Ricardo experienced significant impairment in social interactions and reported poor satisfaction with his social life. These changes were not always reflected in the objective measures; however, the questionnaire along with the assessment measures did capture social and cognitive deficits that tended to relate to reported social satisfaction and involvement.

Many needs were expressed, some explicitly social and other's indirectly related to social functioning. Social needs included making less impulsive decisions, coping with social anxiety,

setting goals, communicating effectively, cognitive problems, self-advocacy, social satisfaction, and social problem-solving. Related needs included dealing with traumatic stress, coping with chronic headaches, fatigue, and limited participation in activities due to a prioritizing of physical needs. These findings are largely consistent with prior literature; however, this study has delineated ways in which these needs impact social outcomes. Even adolescents with mild TBI were impacted by a combination of physical, psychological, and cognitive factors. Each adolescent presented with different combinations of needs and those needs changed over time. For some, friendships changed, and for others enjoyment of social interactions changed, but all changes were the result of a combination of factors.

By analyzing the relationships among social themes, interrelationships emerged as social processes that impacted functioning across time. Immediate changes in the individual and the environment lead to desired environmental changes that enabled the individual and family to adjust to the changes experienced or to ameliorate disability caused by the relationship between the changes in the individual, the changes in the environment, and the given context. A number of factors were identified that make those desired changes easier or more difficult to obtain. The resulting model draws on an ecological framework and implicates the assessment and management of multiple systems to obtain desired social outcomes.

Meeting the social needs of adolescents who have had a TBI is best achieved through assessment and intervention that harnesses environmental resources, mobilizes facilitators of change, and reduces inhibitors of change. Many examples of ways in which needs were met were reported by participants in this study, including psychoeducation, 504 plans and IEPs, family support, and community involvement. To meet these needs, practitioners (e.g., pediatricians,

social workers, school psychologists, speech-language pathologists) may need to address barriers to social participation, physiological issues, educational plans, and limited social opportunities that likely require a multidisciplinary team approach. For example, Ricardo could benefit from increased communication with a medical or behavioral health provider knowledgeable in TBI, pharmacological and behavioral management for possible anxiety and depression, assistance in getting connected with social activities that interest him (including transportation if needed), conversational strategies, and additional academic support to enable him to fully participate in the general education setting. Such interventions could include psychology, psychiatry, social work, speech-language pathology, and special education, as well as necessitate communication and collaboration between providers.

Generally, peers' reactions to the adolescents' injuries were positive, but some negative reactions were described by two participants. Ricardo and his mother described a decrease in Ricardo's friendships and Natalie described the process by which she "realized who her real friends were." Natalie's mother described some of Natalie's friends as not knowing what to do when they interacted with Natalie following her accident. Likewise, Ricardo's TBI was not acknowledged by his school or by peers. This would suggest that peer knowledge about TBI in general and about a child's accident may be important for peer acceptance and future peer relationships. This idea is further supported by Reba, Kelly, and their mother's portrayal of their "church family" as being more aware of the girls' struggles than other peers, and thus more understanding and more positive social interactions.

Assessment

Participants in this study reported high acceptability of the methods used for assessment. One participant reported that she appreciated the opportunity to talk to the researcher in addition to the rating scales and direct measures. The implication here may be the need for partnering these adolescents and families with a professional periodically for time to debrief and ask questions in ways that cannot be accomplished with family or friends. Overall, participants needed little supplementing of technology (one family needed a webcam), internet speeds were adequate for telehealth software, and participants reported no difficulty in the implementation of software or use of hardware. While access and ease of use for this rural sample may not generalize to all rural locations, they are indicators of the feasibility of expanded use of computerized methods data collection. Electronic methods of assessment (as opposed to mailed packets) may have been especially efficient at data collection and have the potential to alter attrition in research or follow-up efforts. This benefit may be uniquely relevant to rural people with TBIs who are less likely to physically meet with specialty health providers that may be located at a distance.

The direct measure of social cognition appeared to capture more variability than the rating scales. The rating scales selected for the study are well researched and validated, and multiple raters were used, but they failed to capture social barriers and difficulties encountered by adolescent participants in this sample. This is consistent with Rosema et al. (2012) findings that suggested studies employing direct measurement of social abilities are more likely to identify deficits than those relying on parent rating scales. Our participant with the greatest amount of social impairment, Ricardo, did poorly on both rating scales and direct measures.

Reba, however, did poorly on social cognition, as well as some other cognitive tasks, but was rated average to above average on parent rating scales. Interviews revealed significant social difficulties that Reba experienced and continues to experience in her social enjoyment, peer reactions, and engagement; although her overall social quality of life remains high. Findings and acceptability of interviews in our study suggests a comprehensive assessment of adolescents with TBI should include adolescent and parent interviews that allow for open responses that capture important areas of need and concern that are not captured in typical assessments.

The inclusion of both parents and adolescents in this study revealed expected differences in the information gathered from each. Adolescents tended to discuss symptom change over time and friendship changes, as well as specific symptoms and factors affecting symptoms. In contrast, parents tended more often to discuss context, attempts to meet needs, and the role of community. Taken together, both perspectives added valuable information to the creation of the emergent model and, again, should be considered essential for assessment, intervention, and research with this population.

Finally, the resulting model provides four broad areas of assessment for adolescents with brain injuries in regard to social processes, changes in the adolescent, immediate changes in the environment, desired environmental changes, and facilitators and inhibitors of change (FIICs). A variety of assessment methods and informants should be used to assess these areas. Assessment of FIICs is one area in which assessment may traditionally undervalue. Considering the importance of these variables in meeting the needs of adolescents, it seems important to assess and monitor them over time as a dynamic assessment of the ever changing effects of TBIs in

adolescents. Interviews and questionnaires seem to be the most likely methods to do this, but future research should address assessment modalities.

The importance of assessing all areas can be seen by taking a closer look at Natalie's case. Natalie performed average to above average on all measures, including all measures of social ability and quality of life. Yet, through interview, several behavioral and relational changes were revealed that could be the target of intervention and support. Interviews with Natalie and her mother indicated that there were changes in motivation and social interaction that affected socialization and decision making that were not captured by typically used social/behavioral measures. Furthermore, her change in associations ("stoner friends") and compromised decision making (bringing marijuana on a school trip) endangered her future and had potentially severe implications. Natalie's mother felt overwhelmed, they were travelling far to medical specialists, and felt they had little access to expertise, leaving her wondering exactly what the impact of the TBI was. Needs were reported by Natalie and her mother (e.g., school schedule adjustments), but can also be inferred (e.g. expertise and communication). An assessment of all areas provides a clear picture of social processes and provides guidance for supports and intervention. Natalie's may also have been a case in which having access to professionals remotely via telehealth software would have provided the kind of support that would ameliorate the mother's concerns and/or provided ways for her to handle the situation effectively.

Educational Implications

Educational themes were the most commonly expressed in this study. Participants expressed many ways in which schools met their needs, made accommodations, plans, and

communicated with parents and other professionals. Participants also expressed many ways in which they encountered barriers to working with the professionals in the school and getting needs met.

Previously discussed assessment implications also apply to school professionals working with adolescents who have TBIs. One comprehensive model of school based assessment that has been proposed is the TBI-SNNAP (Jantz, Davies, & Bigler, 2014). This model is broad and ecological in nature and has an emphasis on communication and collaboration. Further research should demonstrate if it can be implemented effectively and scaled up, and if it sufficiently identifies FIICs and social impacts. Furthermore, educational settings are ideal places for many related aspects of assessment including surveillance, screening, and progress monitoring because of ongoing interaction with both referred and non-referred populations. Considering relatively high base rates of TBI (Schneier et al., 2006), surveillance and screening should be systematically available. To date, most, if not all, large scale screening efforts for TBIs appear related to organized sports.

Formal reintegration and educational plans are an important consideration for schools and families. Rural schools may be more likely to make accommodations without a formal written plan, perhaps due to an increased ease of communication. However, it is difficult to predict long-term effects of TBI and how long supports will be needed or how often they may need to be revisited. One benefit of written accommodations or treatment plans is that they assure reevaluation on a consistent basis. Perhaps training for educators about the long term effects and changes in youth with TBI should be considered since outcomes tend to endure but awareness of the ongoing need does not. Education for peers may also prove useful in certain circumstances

to deter rejection. Reba's case highlights the importance of formalizing a plan, and how a lack of written plan increased reliance on self-advocacy by both parent and adolescent, which is not always possible. Particular attention should be paid to social needs and goals, and plans to meet those needs should be included if indicated. A decision making algorithm proposed by Popoli, Burns, Meehan, and Reisner (2014) includes written plans in the form of a pre-referral or response to intervention team plan, 504, or IEP depending on response to intervention and duration of symptoms. The current findings support a tiered delivery system that can enable responsiveness to immediate needs and ongoing monitoring and flexibility.

Expertise

Expertise was a frequently expressed unmet need by parents. They expressed a lack of knowledge of TBI professionals (e.g. school professionals) from whom they could seek information as well as a lack of ongoing information that could assist them in understanding TBI in the context of ongoing development. The need for expertise was expressed on many levels, including a lack of state-level infrastructure, specialty care, and local knowledge. It is clear that all the participants in this study have benefited from the Montana infrastructure that connected them with the Brain Injury Alliance of Montana, which in turn provided them with information and local resources. The BIAMT regularly contacts referred individuals for three years after their injury. Clearly the BIAMT is addressing a need expressed by several participants, but perhaps it is not fully meeting the need. Perhaps participants are not taking full advantage of this resource, the BIAMT may not be directing them to appropriate resources, or appropriate resources may not be available. Not all states have this infrastructure. There also appears to be great need for

experts in TBI to conduct trainings with primary care providers, school personnel, and other individuals working with adolescents. State infrastructure can assist in supporting that training.

University training programs can also help to address difficulties families have in accessing expertise. School psychologists, in particular, are well positioned to assess the effects of TBI; design and implement interventions and educational programming; initiate referrals to other professionals both in and outside of the school; and facilitate communication among families, schools, and other providers. Participants in this study frequently reported a lack of understanding of TBI from their school professionals. From the school psychology perspective, this problem was likely exacerbated by the lack of formal evaluation and intervention planning for all participants. Two participants did receive a written plan, but one was on an existing IEP and included no additional assessment focusing on the potential impact of the TBI and that other was a 504 plan with no formal testing. Three of the four participants likely did not receive attention from school psychologists and special education professionals (e.g., SLPs, OTs, etc.), those school professionals most trained in exceptionalities, rehabilitation, and intervention planning. However, the extent to which this would have increased consumer confidence in school personnel is unknown. In an older survey of school psychology training programs, only a small percentage reported required training in neuropsychology and half reported that they offer training related to intervention and placement options for students with TBI (Walker, Boling, & Cobb, 1999). Furthermore, few programs that did not offer this training reported intent to add the training. A more recent regarding common misconceptions about TBI, school psychologists in North Carolina performed better than the general public, but still endorsed some misconceptions at rates of over 50% of respondents (Hooper, 2006).

The issue of how to train school psychologists to be more proficient in identifying and working with students who have TBI is difficult. Davies and Ray (2014) examined the effectiveness of a half-day training in TBI for school psychologists, concluding that knowledge did not increase at a one-year follow-up. Given the complexity of presenting concerns and issues in pediatric TBI and the limited effectiveness of brief trainings, it seems likely that school psychologists will benefit more from ongoing training models and increased exposure to professionals with expertise in TBI. Communication among multiple professionals is critical and is a ubiquitous recommendation of models of addressing TBI in schools (e.g., TBI-SNNAP). Exchange of information in interagency collaboration needs to be two-way and outside professionals may need assistance to understand relevant aspects of educational law, policy, and best practices (Chesire, Canto, & Buckley, 2011). It seems reasonable that increased exposure to neurologists, neuropsychologists, and other experts working with youth with TBI that function largely outside of the school systems should begin in training programs. Such a training model would allow for school psychologists to learn about TBI and other forms of neurological impairment and maximize the potential for future collaboration as school-based professionals. Additionally, school districts can work to increase communication and collaboration with experts in brain injury through outreach and formalized collaborations (Chesire et al., 2011).

In addition to training and information, experts can be more available to individual patients and patient families through telehealth. Additional use of telehealth may enable greater expertise to be available to kids and families and allow on-going contact to be more feasible for those living in rural areas. Telehealth communication was acceptable by all in the study who appreciated the contact and opportunity to express their concerns and ongoing needs. Increased

use of technology can also assist in fostering better communication among professionals to provide wraparound services and supports. Ricardo's case illustrates how expertise and school needs are related and how they can be ameliorated by communication. For at least some of Ricardo's schooling, Ricardo's mother had one professional in whom she felt confident (a neurologist). The neurologist reportedly informed Ricardo's mother about school services, but did not have ongoing contact or consultation with the school. Ricardo's mother subsequently expressed dissatisfaction with the school services and felt they did not understand Ricardo's difficulties with the exception of one teacher who had had a brain injury herself. Ricardo's mother expressed several unmet needs with regard to academic functioning and also highlighted an issue with small schools in which students do not have teacher options and may have the same teacher for several years. Furthermore, teachers may have had limited exposure to children with TBIs and have not gained experience and knowledge in that particular content area. Ricardo and his mother's experience is one of wide variability in teacher ability and, subsequently, Ricardo's academic trajectory.

Research

The findings here support the need to include direct measures of social functioning in studies of adolescents with TBIs. Additionally, rating scales, questionnaires, and interviews can supplement direct measures and would benefit from more specifically targeting some of the social processes described here. For example, FIICs emerged as integral factors in the model and seem to be less studied than needs and definitely less studied than immediate changes. Considering that changes in socialization likely emerge more slowly and have a distinctly different developmental pattern than the often focused on cognitive changes, the facilitators and

inhibitors of desired changes seem an important area for inquiry. Examples of research in these areas would be on levels of self-advocacy, the impact of social opportunities and quality of those opportunities, or the content of educational plans for rural adolescents who have had TBIs; searches of the PubMed and PsychInfo databases returned one study directly related to any of these topics (discussed in the literature review of the current study; Heyer et al., 2015)

The present study also piloted a distance assessment protocol using mailed packets, telephone interviews, and telehealth software. Distance methods were employed specifically to target a rural population, a population which has been historically underrepresented in TBI literature. Telehealth appears both viable and particularly useful due to its versatility, convenience, and potential to reduce attrition through efficiency and direct contact. As technology continues to improve, more comprehensive measures will be able to be employed and rural participants should be included more regularly in research.

Limitations

The present study is limited by a very small sample size ($n=7$), that, in the best scenario, captures the experiences of four adolescents and their families. Although inconsistent with incidence estimates, three of the four adolescents were female. All parents involved in the study were also female. The extent to which gender of participants influenced the data collected is unknown. Likewise, the extent to which the experiences of these participants generalizes to other rural adolescents who have had brain injuries is also unknown. As a study that relied heavily on qualitative methodology, the aim of this investigation was to explore in depth the lived experiences of participants. That being said, the pre-specified stopping criterion for recruitment of new participants, two interviews with no new themes, was met.

Participants were all recruited through the Brain Injury Alliance of Montana (BIAMT). The BIAMT had previously provided them with information and local resources and monitors status at regular intervals. The majority of adolescents who experience TBIs likely do not receive a service such as this. Considering the important role of expertise and resource acquisition that emerged in the present study, it is likely that contact with the BIAMT has made an impact in the lives of participants and recovery processes that the current study could not measure without a control sample.

The model that emerged from this study is best interpreted as the result of an interactive process between the researcher and the participants (Henwood & Pidgeon, 2003). Although participants were allowed freedom within the interviews, the original guiding questions were determined by the researcher, and follow-up questions were likely subject to investigator bias, as well as the responses of other participants in the study. Henwood and Pidgeon (2003) use the term “generation of theory” to describe this interactive process. Throughout this study, I have tried to maintain transparency in my biases and theoretical formulations, but the resulting model and conclusions are undeniably a mutual construction reflecting a dynamic and interactive process between the researcher, the adolescents who have had TBIs, and their families.

Contribution

The present study is the first to validate the effectiveness and social validity of telehealth as a mode of assessment and communication for adolescents with TBI and their families living in rural areas. Studies have been done using email intervention for adults with TBI (Kim, Stierwalt, & LaPointe, 2010) and telehealth interventions for parents of urban youth with TBIs (Wade, Walz, Carey, & Williams, 2008). Consistent with previous findings, both parents and adolescents

reported high levels of acceptability and ease of use. Furthermore, the more direct contact achieved through telehealth, as opposed to traditional mail or email, may facilitate more frequent and longer-term follow-up care and less attrition.

This is the first study to focus on rural adolescents with TBI as opposed to urban adolescents. Rural families encounter both similar and unique social issues. Similar to their urban peers, rural adolescents experience cognitive impairment, psychological problems, and physical restrictions. The rural families in the present study discussed several issues that may be unique to or more salient in rural settings. Some of these issues were significant enough to emerge as sub-themes in the overall model; specifically: distance as a barrier to services, availability of expertise for the family, and ability to consult with other professionals working with the adolescent and unique community responses.

The present study demonstrated the importance and acceptability of including interviews with adolescents with TBIs as well as their parents. Both generations contributed unique information. Communication between professionals and with families was an emergent theme in the present study and has been discussed in previous literature as an important component of assessment and intervention. The present highlights the importance of long-term communication and the importance of continuing to include both parents and adolescents in this communication.

Finally, this study describes a model of social processes emergent from the experiences of adolescents with TBIs and their parents. It implicates four domains necessary for a thorough assessment that can facilitate comprehensive intervention. This model includes areas of change and needs and also delineates specific factors that inhibit or facilitate recovery (FIICs).

Future Directions

More research should be conducted on factors that facilitate and inhibit desired changes for adolescents following a TBI. FIICs identified in this study included factors rarely or never researched in adolescents with TBI, including limited social opportunities, the effects and content of written educational plans, and self-advocacy in the recovery process. These factors change over time in appearance and importance and studies will have to be well designed to capture these changes in the context of evaluation and intervention.

Results of this study indicate that remote assessment is feasible, acceptable, and provides potentially useful information. The availability of assessment measures for use in remote assessment protocols is increasing rapidly and research is needed to evaluate the utility and benefits of using these protocols. For example, remote assessment of processing speed is currently available that was not available at the initiation of this study (e.g. Cogstate Detection Task). Future research will need to document specific benefits of the use of remote protocols. For example, identifying areas of deficit may not be useful if appropriate services and knowledgeable providers are not available to rural youth and families.

Several peer and community factors important to both initial and ongoing social processes were identified in the present study. Future research should examine these peer and community dynamics in greater detail. Peer and community knowledge of the adolescent's injury appeared related to peer and community response for the participants in this study. If this finding holds true in a larger sample, it has implications for assessment and intervention. For example, if peer knowledge of TBI is important for positive social interactions, interventions that include peers should be studied. Considering the importance of peer relationships in adolescence and the

prevalence of social impairment in youth with TBI, intervention that includes peers seems particularly promising.

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APPENDIX A

PARENT QUESTIONNAIRE

Date _____ Age _____ Gender _____ Grade _____ GPA _____

1. **Gender*** (Choose one):

- Male
- Female
- Other

2. **Birth date*:** _____/_____/_____
 y y y y m m d d

3. **Age:** ____ years (2-18)

4. **Ethnicity*** (Choose one):

- Hispanic or Latino
- Not Hispanic or Latino
- Unknown

5. **Race Category*** (Choose all that apply):

- American Indian or Alaska Native
- Black or African-American
- White
- Not reported
- Asian
- Native Hawaiian or Other Pacific Islander
- Unknown

6. **Primary language**

- English (eng)
- Chinese languages (chi)
- Other, _____
- Spanish (spa)
- French (fre)
- Sign Languages (sgn)
- German (ger)

6. **Mothers highest level of education:**

- Some High School
- Bachelor's Degree
- High School Degree
- Graduate Degree
- Some College

7. **Father's highest level of education:**

- Some High School
- Bachelor's Degree
- High School Degree
- Graduate Degree
- Some College

9. Mother working Y / N; Occupation:

10. Father working Y / N; Occupation:

11. Parents marital status:

12. Were there any known difficulties with your child's birth? Yes No

If yes, describe:

13. Does your child have a vision problem that requires corrective lens wear (e.g., glasses)? Yes No

14. How far do you currently travel to see a doctor? _____ miles

Education

1. Did your child ever have to repeat any grades? Yes No

If yes, which grade/ grades? _____

2. Was your child ever placed in special education classes? Yes No

If yes, which grade?

If yes, please indicate the disability category:

Medical and Health History

Has your child ever been diagnosed with any neurological condition besides TBI? Yes No

If yes, please list:

Is he or she currently experiencing significant problems with mood (such as anxiety &/or depression) or any other psychiatric condition? Yes No

If yes, please list:

3. Is he or she currently receiving treatment for a mood problem (such as anxiety or depression) or any other psychiatric condition? Yes No

Head Injury
History

Has your child ever experienced a concussion or brain injury?	Yes	No
Did he or she lose consciousness?	Yes	No
If yes, how long was he or she unconscious? (circle one)		
Less than 1 minute	1-15 minutes	
15 minutes to 24 hours	More than 24 hours	
Does he or she remember the events immediately before and after the head injury?	Yes	No
If no, how long of a time period is he or she unable to remember? (circle one)		
A few seconds	Less than 5 minutes	Less than 30 minutes
30 to 60 minutes	More than 60 minutes	60 minutes to 24 hours
1 day to 7 days	More than 7 days	
Glasgow Coma Scale Score (if known) :		
Was brain imaging conducted?	Yes	No
If yes, were abnormalities detected?	Yes	No
If yes, describe:		
6. Were either of the following present: skull fracture?	Yes	No
brain swelling?	Yes	No
7. Was the school your child attending made aware of your child's TBI?	Yes	No
8. Did the school your child was attending receive information about the TBI?	Yes	No
If yes, describe:		
9. Did an exchange of information among people working with my child (for example: between the school and a neurologist) continue after an initial exchange?	Yes	No

If yes, describe:

10. What was the extent to which each of the following factors was a burden to the family in the 3 months following the TBI?

Constraint	Impact 1(very little impact) – 5 (severe impact)				
Time Management	1	2	3	4	5
Financial	1	2	3	4	5
Social Support	1	2	3	4	5
Overall Family Stress	1	2	3	4	5

11. Did you receive any professional support either individually (e.g. counseling) or groups (e.g. a support group)? Yes No

If yes, describe:

12. Is there any support, service, or information that you would have like to have had following your child's TBI? Yes
No

If yes, describe:

Youth Social Functioning

1. How many friends does your child currently have (other peers whom he/she spends recreational time with outside of school or organized clubs and sports)?

Make your best guess.

Currently:

Before TBI:

Did the number of friendships change following the TBI? Yes No

2. Please list all organized peer group activities that your child is involved in:

1. About how many hours per week does your child spend with his or her friends outside of organized activities?

4. Would you be willing to be contacted for a follow-up interview?
 Best way to contact and contact information?

Yes No

APPENDIX B

SOCIAL SKILLS RATING SCALE (ADAPTED)

Please complete the following rating scale based on your child's current social functioning.

	Social Skills	How Often?		
		Never	Sometimes	Very Often
1	Starts conversations rather than waiting for others to talk first.	0	1	2
2	Helps you with household tasks without being told	0	1	2
3	Attempts household tasks before asking of your help	0	1	2
4	Participates in organized activities such as sports or clubs	0	1	2
5	Politely refuses unreasonable requests from others	0	1	2
6	Introduces himself or herself to new people without being told	0	1	2
7	Uses free time at home in an acceptable way	0	1	2
8	Says nice things about himself or herself when appropriate	0	1	2
9	Responds appropriately to teasing from friends or relatives of his or her own age	0	1	2
10	Responds appropriately when hit or pushed by other children	0	1	2
11	Volunteers to help family members with tasks	0	1	2
12	Invites others to your home	0	1	2
13	Avoids situations that are likely to result in trouble	0	1	2
14	Makes friends easily	0	1	2
15	Keeps room clean and neat without being reminded	0	1	2
16	Completes household tasks within a reasonable time	0	1	2
17	Shows concern for friends and relatives of his or her own age	0	1	2

18	Controls temper in conflict situations with you	0	1	2
19	Ends disagreements with you calmly	0	1	2
20	Speaks in an appropriate tone of voice at home	0	1	2
21	Acknowledges compliments or praise from friends	0	1	2
22	Controls temper when arguing with other children	0	1	2
23	Appropriately expresses feelings when wronged	0	1	2
24	Follows rules when playing games with others	0	1	2
25	Attends to your instructions	0	1	2
26	Joins group activities without being told to	0	1	2
27	Compromises in conflict situations by changing own ideas to reach agreement	0	1	2
28	Puts away belonging or other household property	0	1	2
29	Waits turn in games or other activities	0	1	2
30	Uses time appropriately while waiting for your help with homework or some other task	0	1	2
31	Receives criticism well	0	1	2
32	Informs you before going out with friends	0	1	2
33	Follow household rules	0	1	2
34	Is self-confident in social situations such as parties or group outings	0	1	2
35	Shows interest in a variety of things	0	1	2
36	Reports accidents to appropriate persons	0	1	2
37	Is liked by others	0	1	2
38	Answers the phone appropriately	0	1	2
39	Asks sales clerks for information or assistance	0	1	2
40	Appears self-confident in social interactions with opposite-sex friends	0	1	2

APPENDIX C

Neuro-QOL Item Bank v1.0 –Pediatric Social Relations- Interaction with Peers- Short form

Pediatric Social Relations- Interaction with Peers – Short Form

Please respond to each question or statement by marking one box per row.

In the past 7 days...		Never	Almost never	Sometimes	Often	Almost always
NGBOLed11	I felt close to my friends.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
S05R1	I was able to count on my friends.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NGBOLed20	I felt comfortable with others my age.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NGBOLed28	I was happy with the friends I had.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NGBOLed30	I felt comfortable talking with my friends.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
S05R1	I spent time with my friends.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
S05R1	My friends and I helped each other out.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NGBOLed33	I had fun with my friends.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

APPENDIX D

INTERVIEW SCRIPT

The following statements and questions reflect topical areas to be addressed by the interviewer. Due to the nature of conducting semi-structured interviews, having guiding topics will offer the flexibility needed to pursue lines of discussion that emerge in the interview. The interview will commence with an initial statement, listed below, and then address the topical areas.

Beginning of Focus Group Script:

Thank you again for taking time out of your day to speak with me. You have already completed rating scales, questionnaires, computer tests (as appropriate) and have agreed to be interviewed. For approximately the next 60 minutes, I will be asking you different questions to learn more about your (you and your child's) experiences related to the methods I used during this study, as well as your (you and your child's) injury-related experiences. The information gathered from this interview will help to understand what children and families who have brain injuries and concussions go through and how best to help them.

Before we begin, I want to remind you that you have signed a consent to participate in this study and I want to give you the opportunity to ask any questions you might have about that. Do you have any questions about the consent that you signed?

The information that you provide during the interview will be kept confidential. That is, we will make sure that we do not link your name with any information we share through publications or presentations. I will also be audiotaping and taking notes to make an accurate record of what is said. There is no right or wrong answer to the questions that will be raised; the important thing is that you share your experiences and opinions.

The notes and the information you provide will be kept confidential. Only those of us who are involved in the research project will have access to the information we collect. This information will be kept in a locked research lab on the University of Montana campus. No one else outside of the research team will see your responses.

Do you have any questions about the informed consent or how we will be spending the next 60 minutes?

Topical Areas for Questions:

- Social validity and acceptability of assessment methods
- Perceived injury-related needs
- Access and barriers to services and supports
- Injury-related social impact and relevant processes

Main Guiding Questions and Key Topics:

What did you think about the methods I used to assess you (you and your child)?

What did you see as your (your child's) needs: (a) when the injury occurred and (b) after injury treatment?

Tell me about the services and supports you (your child) received following the injury.

Tell me about how the TBI affected you (your child) socially?

Ending the Interview:

Thank you again for taking the time to participate in this important research. As I said before, you will be entered into a drawing for two \$100 prizes. You will also be provided with a summary of strengths and weaknesses identified through these measures and interviews. The drawing will occur sometime between January and May 2015, depending on how many participants need to be included in this research. The performance summary will be mailed to you within one month.

Finally, we want to remind you that your name will be kept confidential and separate from any of your answers in the focus group recordings or notes. If at any point you have any questions or are concerned about your comments being used, please contact the primary investigator, Brandon Rennie, at the contact numbers provided in the informed consent. Do you have any questions before we end? Thank you.

Appendix E

Initial Conceptual Model

