A PRELIMINARY INVESTIGATION INTO THE DEVELOPMENT OF AN INSTRUMENT TO ASSESS DECISION MAKING AMONG PERSONS WITH AND WITHOUT TRAUMATIC BRAIN INJURIES

by

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December, 2020

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This dissertation discusses existing tools for the assessment of decision making in adolescents and young adults who have sustained a traumatic brain injury (TBI) and limitations of these tools. To address these limitations, I developed an instrument named the *Capacity for Decision Making Assessment, Adolescent Version* (CDMA-A) which is presented, along with the initial reliability and validity data for use of this instrument as a measure of decision making. I examined descriptive statistics and internal consistency, and an exploratory factor analysis (EFA) was attempted to examine the structure of the scale. ROC Curves were developed for each item to examine predictive accuracy. In addition, differences between those with and without TBI were examined using independent samples *t*-tests. Other variables examined were sex differences and differences based on severity of TBI and time since initial TBI diagnosis. Findings suggested that participants with no previous history of TBI performed better on the CDMA-A decision making instrument than did participants who have experienced a TBI/concussion in the past. Significant differences were not found among severity of TBI or time since TBI. Issues with the data suggest that additional research is needed to explore scores on the CDMA-A in a larger sample and that revisions to the items may be required before the CDMA-A could be considered a reliable and valid measure of judgment and decision making for adolescents and young adults.

DEVELOPMENT OF AN INSTRUMENT TO ASSESS DECISION MAKING AMONG PERSONS WITH AND WITHOUT TRAUMATIC BRAIN INJURIES

A Dissertation

Presented to the Faculty of the Department of Psychology

East Carolina University

In Partial Fulfillment of the Requirements for the Degree

Ph.D. Health Psychology,

Pediatric School Psychology concentration

by

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ACKNOWLEDGEMENTS

I would like to thank my family and my husband for all their support and encouragement throughout this process. I would especially like to thank my husband for being such a nerd that he could help me with my statistics by teaching himself to write the code for a ROC Curve Analysis.

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CHAPTER I: LITERATURE REVIEW

Problem Overview

At least 2.8 million Traumatic Brain Injuries (TBIs) occur every year in the United States, mostly affecting children and the elderly (CDC, 2015). Traumatic Brain Injuries often result in deficits in executive functions, which include impaired decision making and judgment (Perna, Loughan, & Talka, 2012). Decision making can include medical decisions, decisions regarding consent to treatment, financial decisions, and decision making affecting the ability to drive, to living alone, and to return to work or school. Clinical decisions regarding a person's capacity for decision making are often preceded by a doctor's approval. This requires the doctor to perform an assessment of the individual's capacity to make decisions. Rabin, Borgos, and Saykin (2008) surveyed 290 neuropsychologists online and found that 89% assessed judgment when evaluating patients with TBIs. Judgment and decision making are important to assess because individuals with TBIs want to resume daily activities such as driving, making financial decisions, and living independently. However, they may also have limited insight into their impairment, their ability to live independently or ability make independent decisions (Spikman & van der Naalt, 2010; Choiu, Carlson, Arnett, Cosentino, & Hillary, 2011). Thus, the ability to assess decision making and judgment is paramount in examining whether an individual can resume these activities.

Because many TBIs occur in the adolescent and early adult population, assessment of decision making in this population is important. This population is unique compared to that of the elderly because they will have more years (presumably) left in their lives that will require decisions to be made. Furthermore, there is a strong intrinsic need for independence at this developmental stage (Inguglia et al., 2015). Unfortunately, research on decision making in this population is limited, particularly when considering factors specific to the TBI population. There are several issues surrounding the assessment of decision making in adolescents/early adults. First, there are problems with the psychometric properties of current instruments used to assess capacity for decision making. Second, many instruments used to assess decision making have been normed on adult populations and may not be appropriate to use with adolescents and young adults. Furthermore, adult and elderly populations often suffer from various types of dementia, not TBIs (McDougall & Mansbach, 2013). Third, many factors play a role in assessing decision making ability of TBI patients that are not assessed in the current instruments available. Factors such as severity of TBI and time since injury are specific to the TBI population and affect decision making in the short-term and long-term (Dreer, DeVivo, Novack, & Marson, 2012; Marson et al., 2005). Another problem with more recently developed instruments for decision making is their narrow scope. There are instruments that assess financial decision making (Dreer et al., 2012; Martin et al., 2012) or medical decision making (Marson et al., 2005), but no instrument combines different types of decision making, particularly on an adolescent/early adulthood level. Finally, the instruments that have been studied in the adolescent TBI population include a modified version of the Iowa Gambling Task, which asks subjects to choose a deck of cards in the context of winning or losing money. It measures decision making regarding understanding gains and losses but does not include real world situations like those they will encounter if living independently (Schmidt et al., 2012; Hanten et al., 2006). Further discussion of these deficits in previous research is presented below.

Instruments Commonly Used to Assess Decision-Making After TBI

According to Rabin and colleagues (2008), 89% of neuropsychologists assess judgment in TBI patients, and 87% advocated for improvement in tools used for assessing judgment. The most common instruments used by these neuropsychologists when assessing judgment were the *Wechsler Adult Intelligence Scale, Third Edition* (WAIS-III) comprehension and similarities subtests, and the *Wisconsin Card Sorting Test* (WCST), which are developed as measures of cognitive ability and executive function, but not for the explicit purpose of assessing decision making capacity. Instruments that are marketed as assessing judgment and decision making are much less common. For example, the *Cognistat* was used by 15% of neuropsychologists, the *Neuropsychological Assessment Battery* (NAB) Judgment and Daily Living subtest was used by 6%, and the Problem-Solving scale of the *Independent Living Scale* (ILS) was used by 12%. Some of the reasons for the infrequent use of these instruments include poor psychometrics (e.g. Cognistat judgment questions) and the costs of buying an entire battery of assessments just to use one subtest or scale (Rabin et al., 2008).

The NAB Judgment subtest lacks sufficient research on the psychometrics of the instrument. The instrument was normed with a sample of participants from an Assisted Living Facility, with a focus on patients with dementia, not those who have experienced a TBI (McDougall & Mansbach, 2013). Additionally, the psychometrics for the judgment questions of the *Cognistat* are questionable due to the limited number of questions; it has only three questions that assess judgment, which does not allow one to evaluate decision making in different areas of life. For example, *Cognistat* questions do not directly assess judgment and decision making regarding one's health and safety or medical and financial situations (Rabin et al., 2008). Another concern with the *Cognistat* instrument is that the items are outdated. For example, one judgment item asks what to do if a person is stranded at the airport with one dollar. For adolescents in the current generation, they are likely to reference using a cell phone as opposed to a payphone because many of them have never encountered a payphone.

Another psychometric problem with many instruments that do assess judgment and decision-making center around issues of norming populations. For example, the ILS has good reliability and validity; however, it is normed on populations of 65 years and older and is mostly used for patients with dementia, not patients with TBIs (Rabin et al., 2008). Other assessments are often used on populations with dementia, psychiatric diagnoses, and medically ill patients whose illnesses are not specifically disclosed (Lim & Marin, 2011). The need for an assessment of judgment and decision making with stronger psychometric properties, a wider array of questions, and availability outside of purchasing an entire battery of instruments is clear.

Defining Decision Making

Decision making has been defined as "the act or process of deciding something" (Merriam Webster, 2020). Decision making occurs when one must select a choice when given various options. Decision making often involves weighing the consequences of each option and considering all alternatives (Missier, Mantyla, & Bruine de Bruin, 2010). Brand and colleagues (2006) developed a model of decision making under risk, which suggests that executive functions are involved in decision making strategies like analyzing options, planning, assessing probabilities, and selecting information (Schiebener et al., 2014). Some common components of executive functions include working memory and recall; activation, arousal, and effort; controlling emotions; complex problem solving; shifting and inhibiting; organizing and planning; and monitoring. As decision making involves making a choice after weighing options, it is easy to see how the executive functions listed above play a role in effective decision making (Swami, 2013). Decision making has been closely linked with executive functions, with studies finding that deficits in executive functions have been associated with poor decision making (Ochoa et al., 2013). Studies have shown that executive functions such as response inhibition, cognitive flexibility, and impulsivity have been correlated with deficits in decision making on the Iowa Gambling Task in pathological gamblers (Ochoa et al., 2013). Research has shown that although executive functions may be correlated with decision making, decision making is a separate construct that involves the capacity to make a choice after evaluating alternatives and consequences.

Decision Making in Consent Capacity as a Model

Other instruments designed to assess specific types of decision making do exist for patients with various diagnoses. Consent for treatment is one area in which several assessments exist. Research for decisional capacity for consent to treatment has highlighted four pillars of capacity including: (a) ability to express a choice; (b) understanding relevant information; (c) appreciation of the situation and possible consequences; and (d) ability to rationally manipulate information (Appelbaum & Grisso, 1988). Ability to make a choice simply entails the individual being able to express a choice when given options, as opposed to being so indecisive that no decision can be reached. Ability to understand relevant information consists of understanding one's diagnosis, treatment choices, benefits and risks, and any other relevant information to the patient's situation. Patients can demonstrate this ability by paraphrasing information given to the them. Appreciation involves insight into one's illness and understanding of the consequences and implications of their decision regarding treatment. Finally, rationally manipulating information examines whether a patient uses a rational or logical process to make decisions (Appelbaum & Grisso, 1988).

There are four instruments which are commonly used to assess decisional capacity for consent to treatment. The *MacArthur Competence Assessment Tool for Treatment* (MacCAT-T) is a popular, semi-structured interview that assess all four components of capacity. It has been used with populations who have diagnoses including schizophrenia, dementia, major depressive disorder, and those who are hospitalized for medical illnesses. The *Capacity to Consent to Treatment Instrument* (CCTI) is also a semi-structured interview which has two vignettes that cover the four components of capacity. It has been used for patients with dementia and Parkinson's disease. The *Hopkins Competency Assessment Test II* (HCAT) presents patients with an essay describing informed consent and power of attorney. Patients then answer six questions based on the information they read. This instrument only assesses understanding but has been used on populations who are medically ill, have psychiatric diagnoses, have dementia, or are nursing home residents. Finally, the *Aid to Capacity Evaluation* (ACE) is a semi-structured interview which covers the components of understanding and appreciation and rules out that the final decision is affected by psychosis or depression. Each of these instruments has been found to have high interrater reliability and to be valid for assessing consent for treatment. However, these assessments do not cover other areas of decision-making outside of those regarding medical treatment (Lim & Marin, 2011).

Although the instruments described above do assess decision making, they are specific to decision making regarding medical treatment, or decision making affected by psychiatric symptoms. The instruments are not specific to examinees who have experienced a TBI and do not assess general decision making in everyday life. Research suggests the need for an instrument that would better assess decision making in adaptive functioning skills for individuals who have experienced a TBI.

Decision Making and Severity of TBI

Another challenge for studying decision making within the population of individuals who have sustained a TBI is that severity varies dramatically. Research on decision making tends to focus on moderate and severe TBI (Dreer, DeVivo, Novack, Krzywanski, & Marson, 2008; Wood & McHugh, 2013; Hanten et al., 2006), but there are important differences among those with mild TBI. Although mild TBI (mTBI) is associated with lesser global deficits, executive functions are often affected (Catale, Marique, Closset, & Meulemans, 2009; Erez, Rothschild, Katz, Tuchner, & Hartman-Maeir, 2009), and executive functions play a big role in decision making capacity (Satish, Streufert, & Eslinger, 2006). Thus, is it important to distinguish between various levels of severity of TBI and note the differences in decision making across levels. This will be beneficial when designing interventions to assist with decision making capabilities to examine whether decision making can improve with intervention. Likewise, more research is needed to explore decision making in mTBI populations who do not outwardly present with severe symptoms but are likely to have issues with decision making.

In addition, recovery time for the TBI population plays a role in the capacity for decision making. Decision making may be more impaired in the acute phase of injury, but then recover in the months following. Studies have found improved decision making six months post-TBI (Dreer et al., 2012; Marson et al., 2005). Marson and colleagues (2005) examined patients during initial hospitalization for their TBI and found that adults post-TBI performed on par with controls in being able to communicate and make a reasonable treatment choice when the alternative was unreasonable. However, post-TBI adults had significant deficits in appreciating consequences of their decisions compared to controls both at initial hospitalization and at six-month follow-up, even though their ability to appreciate consequences improved over that six months. Thus, while improvements were made in each of these areas, post-TBI adults continued to demonstrate difficulty appreciating consequences of their decisions. Furthermore, research suggests that the predictors of impairment vary regarding time since injury. Dreer and colleagues (2008) found that short-term memory predicted performance on medical decision making in the acute phase of TBI, while executive functioning and working memory predicted improved capacity six months post-TBI. Martin and colleagues (2012) found that working memory and immediate verbal memory predicted performance of financial decision making at the acute phase and working memory and executive functions predicted performance at six-month follow-up. So not only does decision making improve with time, but the predictors of performance may also change with time. This information can be extremely important when working with a patient whose current decision making is impaired, but who may regain or improve capacity for decision making in the months following a TBI. It can be an important motivator for a patient who can work their way toward living independently in the months following their injury.

Types of Decision Making Assessed in TBI Patients

There are different types of decision making that have been studied through previous research. Research on instruments assessing decision making and judgment of patients with TBI has tended to focus on one decision at a time. For example, Dreer and colleagues (2012) used the *Financial Capacity Instrument* (FCI-9) to assess capacity to make financial decisions in 24 adult patients with moderate to severe TBI compared to 20 healthy controls during the acute phase of injury and at six-month follow-up. The FCI-9 has nine domains and two global scores. Ratings of impairment include intact, marginal, or impaired. During the acute phase of injury, patients with TBI performed significantly worse than controls on both simple and complex financial domains. Tasks ranged from basic monetary skills to bill payment and investment decision making. At six-month follow-up patients with TBI performed better on more basic financial skills such as basic monetary skills and cash transactions. However, they continued to perform significantly lower on more complex financial tasks. It is interesting to note that within the TBI group, there was improvement from Time 1 assessment to Time 2 assessment. The group performed better on seven of nine domains and both global scores, suggesting an improvement in decision-making capacity as the brain recovers from injury. Martin and colleagues (2012) also used the FCI and found that FCI performance could be predicted by working memory and immediate verbal memory at the acute phase of injury and executive functions and working memory at the six-month post-injury phase of recovery.

Other studies have focused on the capacity to make medical decisions or consent to treatment. Marson and colleagues (2005) used the *Capacity to Consent to Treatment Instrument* (CCTI) on 24 adult patients with moderate to severe TBI and 20 healthy controls in the acute phase of injury and at six-month follow-up. In the acute phase, TBI patients performed equivalently on tasks of communicating choices and making a reasonable choice when the alternative in unreasonable. However, they scored significantly worse than controls on appreciating consequences, understanding treatment situations and choices, and reasoning about treatment. At six-month follow-up they improved on those three standards within their group but remained significantly below controls in appreciating consequences and understanding treatment situation and choices. Tribel and colleagues (2012) also used the CCTI on 86 adult patients with TBIs (of all severity) and 40 healthy controls one month after surgery. The mTBI group and controls did not differ significantly on any standards. The moderate TBI group was impaired on tasks of understanding treatment and choices. The severe TBI group was impaired on almost all standards, indicating that severity of TBI affects ability to reason in medical decision making.

Decision making in social situations has recently been studied in individuals who have experienced a TBI. Gagnon et al. (2013) studied decision making in adult participants who have experienced a TBI regarding social situations and inappropriate social behaviors. Participants included individuals with a TBI who have presented with inappropriate social behaviors (TBI-ISB), individuals who have experienced a TBI with appropriate social behaviors (TBI-ASB), and controls. Although the sample size was small (32 participants), the research found that TBI-ISB participants had higher scores on the likelihood of engaging in an inappropriate behavior and did so even while recognizing that the inappropriate response would anger others and lead to embarrassment. The participants were read 12 scenarios three times with each scenario having a different behavioral response. They were asked to guess the likelihood in which they would respond in the manner read and then the likelihood that their response would be met with anger from the others in the scenario and embarrassment from themselves, using a Likert scale system. It should be noted that in this study the participants were given the responses to each situation, with some being appropriate and some being inappropriate. So, even though they rated how likely they were to engage in each response, the responses were preselected by the researchers and participants were not asked to initiate their own response to the situation (Gagnon et al., 2013).

Although the studies listed above use instruments designed for assessing decision making ability, they were limited to a specific type of decision such as medical, social, or financial decision making. However, evaluations for a person's capacity for decision making requires assessment of that person's ability to make decisions in various areas that include financial decisions, medical decisions, decision involving daily living skills and interpersonal decision making (i.e. making decisions in social situations). Decision making across these domains would present a robust and detailed assessment of overall decision making and speak to the person's ability to independently make decisions in all the areas mentioned above. It could also differentiate between a person's ability to make reasonable decisions in one area, while having difficulty making decisions in another area (e.g. medical versus financial). There is a need for an instrument that can assess overall decision-making ability across many domains.

Age and Decisional Capacity

The studies described above focused on judgment and decision making in adults, not in pediatric patients. The question of whether adolescents have the decisional capacity of adults is an issue that has been studied recently (Chenneville, Sibille, & Bendell-Estroff, 2010; Partridge, 2013). Questions examine at what age adolescents demonstrate capacity for decision making, and how much decision making are adolescents allowed while still protecting them from poor decisions with possible dire consequences. In his article about the mature minor, Partridge (2013) noted an increasing tendency to assume adolescents over the age of 14 have the decisional capacity to consent to treatment. He points out that contrarily, the Supreme Court recognizes that adolescents lack maturity and sense of responsibility to have the same criminal culpability as adults. There is a debate of whether adolescents should be held to different levels of decisional capacity based on different situations or at different ages. Chenneville and colleagues (2010b) found a significant difference in decisional capacity between children ages 7 to 11 and those ages 12 to 17, with children ages 7 to 11 having less understanding of a diagnosis than older children. There remains a debate over how much autonomy and decisional capacity to give a child, regarding medical decision making, and still using the parent as a protector for that child. This debate becomes even more muddied because there are situations in which a child can consent to treatment without parental approval (i.e. HIV testing, birth control) (Chenneville et al., 2010a). Perhaps because of this debate, there have been limited studies conducted to assess decisional capacity in adolescents.

Instruments Used to Study Decision Making in Adolescents and Early Adults

Some studies of pediatric populations have used a modified *Iowa Gambling Task* (IGT) to assess decision making (Hanten et al., 2006; Schmidt et al., 2012). The modified IGT used in these studies consisted of four decks of cards, with two decks offering small rewards and small losses, while the other deck offered large rewards and large losses. The decks with smaller wins and losses are considered advantageous, and the large loss decks were disadvantageous. Researchers examined the proportion of advantageous decks chosen. Schmidt et al. (2006) compared TBI patients ages 7-17 with orthopedic injury (OI) patients of the same age. Over two years, the OI patients generally outperformed the TBI patients. In addition, over two years of the study, the TBI patients did not show steady improvement in the task, as did the OI patients. Although these studies demonstrate the deficits in decision making of TBI in pediatric patients, it does not examine judgment and decision making in hypothetical situations that may be experienced in the real world. It is this type of decision making that is important for adolescents or young adults who wish to get their driver's license, return to school or work, attend college, or live independently. When doing these things, adolescents are faced with having to make real world decisions (with real world consequences) and take into consideration many different factors that go well beyond choosing a card from a deck.

Cook and colleagues (2013) assessed the ability of adolescents with and without TBI to predict social action and consequences in video vignettes. The children watched short videos that placed avatars in both legal and moral dilemmas. Typically developing children and children with moderate to severe TBIs were both able to predict what the avatar might do in a legal dilemma (e.g. using a fake ID) and a moral dilemma (e.g. cheating on a test) and the reason they might behave that way, without significant differences. It is noted that the children with TBIs had lower scores. Both groups were able to list a similar number of short-term consequences when watching avatars make decisions in legal and moral dilemmas; however, the children with TBI did not perform as well as typically developing children when considering the long-term consequences of the avatars' decisions. These findings were with children who were at least one year removed from their TBI injury, thus significant recovery would have occurred since injury. It is also important to note that while the children were selecting options for what might happen and consequences for decisions, they were not required to make the actual decision of what *should* happen or what they themselves *would* do in that situation. This is an important distinction because even if they can recognize what might happen in a scenario, it may not lead to them making the correct/best decision in that situation. There is a difference in knowing what could happen in a situation happening to someone else and deciding how to act in a situation that is happening to one's self.

The studies above are not designed to assist in assessing the possibility of returning to school or living alone (as they may at age 18, or in college). One such study did examine capacity to return to school for college-aged servicemen who had sustained a TBI. The study was conducted through a VA medical center. The three participants attempted a simulated college course that was 16 weeks long with twelve, hour-long lectures and four examinations. Findings demonstrated a lack of insight of two patients regarding their expectations for performance on the program and their actual performance. Although the simulated experience may have increased awareness of the ability to return to school, the young men refused to admit that their performance was impacted by the deficits resulting from their brain injuries. The study highlights role of insight and awareness when making the decision of whether or not to return school, and considering the consequences of all options (i.e. waiting to return to school, not returning to school, taking one class instead of three, etc.) when making a decision such as returning to school (MacLennan & MacLennan, 2008). This study was informative and used a valid and reliable way to measure decision making regarding ability to return to school. However, the length and intensity of this study demonstrate that it is not an easily administered or efficient way to assess decision making, or ability to return to school.

A study by Rapport, Bryer, and Hanks (2008) studied driving and community integration in a sample of 261 post-TBI adults (ranging from three months to 15 years post-TBI). The study used the *Barriers to Driving Questionnaire*, *Driver Survey*, *Community Integration Measure*, and *Craig Hospital Assessment and Reporting Technique* to assess how driving post-TBI impacted community integration and the differences in drivers and nondrivers post-TBI. The study used mostly self-report measures, but also included a battery of tests to measure neuropsychological functioning. Although the study was not designed to assess decisional capacity, *per se*, results revealed interesting findings that relate to decision making and insight of patients post-TBI. Nondrivers who were not attempting to resume driving generally did not rate themselves as fit to drive and reported more physical, cognitive, and psychological obstacles to driving than nondrivers who wanted to resume driving. However, the majority of nondrivers who wanted to resume driving felt they were fit to drive (88%) and perceived themselves as having similar cognitive and physical profiles to drivers, despite having cognitive functioning that was on level with nondrivers who did not seek to resume driving and significantly worse than survivors who were driving. These findings speak to the lack of insight that patients who have experienced a TBI often experience regarding the deficits and limitations they face post-TBI. Regarding the model of decisional capacity these patients may struggle to demonstrate an appreciation for their diagnosis and for the lasting effects of that diagnosis.

the *MacArthur Competence Assessment Tool for Treatment* (MacCat-T) was used to assess medical decisional capacity in 25 children with HIV and 25 controls (Chenneville et al., 2010b). Children in the control group were given the scenario of experiencing Strep Throat, while children with HIV were asked questions based on their diagnosis. Results indicated that children in the concrete operational stage, according to Piaget (ages 7-11) had significantly lower scores in understanding than children in the formal operational stage (ages 12-17). However, there were no significant differences in scores between the clinical and control groups. It was noted that overall, scores on the understanding and reasoning domains were lower relative to scores on the appreciation and expression of choice domains. This information is useful for understanding ages at which children may have better decisional capacity; however, the assessment is again based solely on their ability to consent to treatment. Additionally, children with HIV may not have the same deficits as children who have experienced a TBI and their ability to live independently may not be questioned as frequently as a child who is post-TBI (Chenneville et al., 2010b).

Summary and Purpose of the Study

Based on research review, it appears that the assessment of decision making and judgment in children with TBI is lacking a brief, stand-alone instrument that can assess decision making in several capacities (i.e. finances, self-care, school, safety, health). As mentioned above, many of the instruments and tasks used today are geared toward adult populations, do not consider the issues specific to TBI patients, and do not assess real world decision making. An instrument of this type could be useful when gathering objective data to assist in clinicians' decisions about a patient's ability to drive, return to school, and live independently. In addition, it would allow for this type of assessment by using one comprehensive instrument, instead of multiple instruments, or one scale from a large battery that may be expensive and unnecessary. The data can also help raise awareness of deficits and lack of insight for parents and the patients themselves.

The goal of this study is to examine the psychometric properties of a newly created, standalone instrument for decision making in adolescents and young adults who have recently experienced a TBI. This study tested an instrument, *Capacity for Decision Making Assessment, Adolescent Version* (CDMA-A), on both nonTBI and TBI populations, with the purpose of assessing reliability and validity of the CDMA-A and whether there is a difference in decision making skills between nonTBI and TBI populations. Additional research questions include whether there are sex differences both between and among groups, as well as differences among varying degrees of severity of TBI and time since TBI.

It is hypothesized that this instrument will demonstrate differences in decision making skills between the TBI and nonTBI population, with nonTBI participants scoring higher on the CDMA-A. It is also hypothesized that the CDMA-A will identify differences in decision making skills based on severity of TBI and time since TBI, with lower severity and greater time since TBI being positively correlated with scores on the CDMA-A. It is expected that sex differences will reveal that males are more likely to take risks when making decisions, and therefore possibly make poorer decisions in some instances. Previous research with the *Iowa Gambling Task* has shown males with and without TBI to be more likely to take risks when making decisions compared to females (Schmidt et al., 2011). It is hoped that this instrument could also be used as a tool for capacity for decision making evaluations and as a progress monitoring tool to assess for capacity to make decisions at a six-month or year follow-up (if the age of the subject remains comparable to the norms).

CHAPTER II: METHODS

Instrument Development

The *Capacity for Decision Making Assessment, Adolescent Version* (CDMA-A) is a 29-item assessment developed by the primary investigator, which presents participants with 24 scenarios for which they are required to make a decision of what action to take (See Appendix A). The remaining five items require the participant to accurately read a class schedule and answer questions based upon the given schedule. The items on the CDMA-A correspond to scenarios related to School, Health and Safety, and Finances. These three areas are thought to be important areas for adolescents and young adults who are beginning to gain their independence from their parents; they are also three areas that could be greatly affected by a traumatic brain injury. Each scenario gives a brief situation after which the participant is asked “What would you do?” Questions are open-ended; requiring the respondent to initiate the decision-making process himself or herself, as opposed to choosing from a list of decisions. This is important for a person who desires to live independently, but has difficulty making a decision without being given choices. Living alone suggests that there will not be someone around to give choices when a decision needs to be made. Answers are scored based on the quality of the response. Answers may be allotted 0 to 2 points. This scoring system is modeled after the scoring system for previous assessments for decisional capacity for consent to treatment, such as the MacCAT-T and also subtests such as the Vocabulary and Similarities subtests on the *Wechsler Intelligence Scale for Children, Fourth Edition*. A 2-point answer is thoughtful, realistic, logical, and gives the best solution to the problem. A 1-point answer is more impulsive, unrealistic, or less helpful. These answers may be vague and not thoughtful, such as borrowing money from a friend, as opposed to budgeting and saving your own money. Vague one-point answers can be queried for further clarification. A 0-point answer is one that is dangerous, lacks any planning, and will not solve the problem. Answers such as “I don’t know” or “Nothing” are also given 0 points, if no other answer is given after one prompt. Scenarios with multiple answers are graded based on the initial answer, which was thought to be the first impulse of the person making the decision. Sample answers worth 0, 1, and 2 points will be provided for the administrators and scorers to increase reliability.

In addition to the 29 previously described items, there is a 22-item Self-Care Assessment to be completed by the patient and by the patient’s parent/guardian or caregiver. This assessment lists 22 self-care activities such as bathing, dressing, cooking, cleaning, ambulation, driving, managing a budget, etc. The caregiver answers each item based on whether the patient can complete the task “with full assistance,” “with some assistance,” or “with no assistance” needed. The information can be beneficial when comparing the caregiver’s answers to the patient’s answers on the CDMA-A. A large discrepancy between the two scores could indicate a lack of insight in the patient regarding their ability to complete these tasks, questionable reliability of the patient’s answers if they are attempting present themselves as being more independent than they truly are post-TBI, or a parent underestimating their child’s ability to be independent post-TBI.

Evidence for Content Validity

The CDMA-A underwent content validation from colleagues in the field of neuroscience. Content Validation was sent to 30 colleagues who have published and studied in the field of neuropsychology. Two colleagues completed the content validation form. It should be noted that there was no incentive offered for responses and the responses were time consuming given the nature of the instrument (51 total items, with 24 being scenarios to read). Content validation of an instrument is conducted to determine the extent to which the items on the instrument are relevant to the construct in question and are adequately sampled from the construct content based on judgment of experts in the field of that content. Ratings were taken to measure the category in which each item belongs, the certainty the respondent had in choosing a category, and the relevance of the item. The content validation form asked each rater to select a category for which that item is determined to belong with choices being school, financial, health and safety, self-care, and none of the above. Each rater then selected the certainty with which they chose the category (e.g. not sure, somewhat sure, very sure). Finally, each rater chose the relevance of that item to the chosen category by selecting "not relevant," "somewhat relevant," and "very relevant." For all 51 questions, both respondents rated themselves of being "somewhat sure" or "very sure" of their categorization of the items. In addition, both respondents rated all 51 items as being "somewhat relevant" or "highly relevant."

Content validation also included a measure known as the Factor Validation Index (FVI). The FVI reflects consensus among experts regarding correctly placing the items in the corresponding category. Fourty-five out of 51 items were placed in the correct category by both respondents. Of the six items on which the two experts disagreed, five of the six items were chosen by one respondent to correspond to the health and safety category, and the other respondent identified the item as one of self-care. Two of these items centered on issues of medication compliance. One item asks a hypothetical situation regarding medication compliance. The other item is intended for the participants' caregiver to answer whether they feel the participant can take medication as prescribed. The item is intended to give both the participant's ability to make a decision regarding their medication and the caregiver's opinion of the participant's ability to take their medication. This distinction was not made known to the respondents of the content validation. Two other questions related to the participant's ability to ambulate independently and to follow a restricted diet. These questions are also intended to be asked of the caregiver regarding self-care, but it can be understood how the statements may be regarded as issues of health and safety. How to respond upon realizing one will be late to a doctor's appointment was rated as an issue of health and safety by one respondent and as a self-care issue by the other. This question was originally intended to be one of health and safety. It is likely that if the respondents had been aware of the caregiver versus patient subtests, they may have been more easily able to distinguish between the self-care and health and safety questions.

Regarding qualitative feedback on the CDM-A, one respondent noted that additional questions focusing on peer interaction and behavioral situations in school would be helpful, with perhaps fewer questions focusing on interpreting a school schedule. The issues of peer interaction and reading social situations were also mentioned as areas lacking assessment by the second respondent. The first respondent also mentioned the need to address issues of drugs and alcohol (i.e. risks involved, following the doctor's advice). Questions regarding these issues were added to the school and health and safety categories, respectively.

Participants for Construct Validity Study

Participants included 100 adolescents and young adults ages 17-22 who were recruited by flyers advertising the study and via undergraduates enrolled in Introduction to Psychology courses at a four-year college in the southeastern region of the United States. Nineteen participants had TBI and 81 participants were nonTBI. College students in the Psychology courses earned points toward their grade for volunteering to take part in research studies on campus. Participants signed up for the research study online and selected a time to complete the instrument. High school students were recruited via a flyer that was emailed out from the principals to the students' email accounts. Students were given information about the study and a number to call to participate. Other participants were recruited from Cherry Hospital, an inpatient regional psychiatric hospital, where the primary investigator works. Initially, the study was intended to recruit participants ages 15-22, but no participants in age range of 15 or 16 were ultimately recruited. The response rate for the CDMA was 100%, where everyone who was asked to complete the study, did so. Demographics for the final sample are listed in Table 1.

Procedures

IRB approval was obtained by East Carolina University's review board. During the consent process, participants who previously experienced a TBI had the study explained to them and/or their guardian and were asked to voluntarily participate in the study. Once consent and assent were obtained, each participant was individually administered the instrument and completed the self-care form and demographics form. The demographics form included questions regarding the date and/or age of the participant when they experienced a TBI, the cause of the TBI, and the severity of the TBI. For the purposes of this study, the Caregiver form was not given to participants over 18 without a TBI. First, caregivers were not available for the participants. Second, because this population consisted of college students, it is assumed that their ability to complete self-care skills (ambulation, hygiene, grooming) was intact. Thus, the demographics form and 29-item instrument to assess decision making was administered to both TBI and nonTBI participants, while the Caregiver self-care skills form was only administered to caregivers of the TBI participants. Additionally, for those participants who had experienced a TBI, the Wechsler Reading Achievement Test – Fourth Edition (WRAT-4) Word Reading Subtest was administered as a measure of premorbid abilities. Studies have shown that tests like the WRAT-4 Word Reading Subtest are described as “hold tests” meaning that reading abilities are minimally affected by brain injuries as compared tasks measuring more fluid intellectual abilities. (Orme et al., 2004). These types of tests are widely used in clinical settings to estimate premorbid ability due to their ease of administration, reliance on previous knowledge (as compared to current cognitive functioning), and moderate to strong correlation with intelligence (Olsen et al., 2015). The WRAT-4 word reading subtest consists of a list of words which increase with difficulty and unfamiliarity that the participant must read aloud and is scored for correct pronunciation. After ten consecutive incorrect pronunciations, the subtest is terminated. Having a measure of premorbid abilities would help to rule out that a previous intellectual disability may be a confounding variable that could impact scores on the CDMA-A.

Table 1

Descriptive Statistics for Participant Population

	TBI N = 19		nonTBI N = 81		Total N = 100	
	Frequency		Frequency		Frequency	
Sex						
Male	15		39		54	
Female	4		42		46	
Ethnicity						
Caucasian	5		40		45	
African American	12		26		38	
Latino/Hispanic	2		5		7	
Asian/PI	0		5		5	
Multiracial	0		5		5	
Grade						
High School	16		5		21	
College	3		76		79	
	M	*SD*	*M*	*SD*	*M*	*SD*
Age	19.84	1.64	18.86	1.19	19.05	1.34
WRAT WR Score	86.53	14.05	107.77	10.90	103.73	14.21

CHAPTER III: RESULTS

Item Analyses Preliminary to Factor Analysis

Participants answered all items on the 100 CDMA-A instruments analyzed. Descriptive statistics for each of the 29 items of the CDMA-A are presented in Table 2. The range, mean, standard deviation, skew, and kurtosis of each item was analyzed to assess for normal distribution of scores. The minimum and maximum range of scores was 0-2, which coincides with the scoring of the answers. It should be noted that *Item 6* had a variance of 0.00 due to all scores being a two. The EFA could not be completed with this item included, thus the item was removed for the remainder of the analyses. The mean for scores on the remaining 28 CDMA-A items ranged from 1.10 to 1.96. The standard deviation of scores for items ranged from .281 to .965.

Reliability

Reliability of the 28-item CDMA-A instrument was analyzed by examining the internal consistency (Cronbach's α). Cronbach's α coefficients range from 0 to 1.00, with coefficients closer to 1.00 indicating greater internal consistency. Results indicated that the α for the total scale was equal to .67. A general accepted rule is that α of 0.7 indicates an acceptable level of reliability, and 0.8 or greater a very good level (Taber, 2017). There were 22 items that had a Corrected-Item Total Correlation below .3 and six items that had Corrected-Item Total Correlations below .1. When those latter six items were removed, the Cronbach's α for the CDMA-A scale rose to .717, which is considered acceptable in most social science research situations (Taber, 2017). For this reason, the analyses of group differences were run using the 22-item version of the CDMA-A. Reliability scores were taken for each of the three subscales of the CDMA-A in addition to the total 22 items. Cronbach's α for the Social Scale was .445.

Table 2

Descriptive Statistics for Each Item of CDMA

Item Description	N	Min. Score	Max. Score	Mean	SD	Variance	Skewness Statistic	Skewness Std. Error	Kurtosis Statistic	Kurtosis Std. Error
Forgot HW	100	1	2	1.10	.302	.091	2.707	.241	5.439	.478
Offend a Friend	100	0	2	1.77	.548	.300	-2.338	.241	4.413	.478
Study or Beach	100	0	2	1.45	.539	.290	-.193	.241	-1.155	.478
Boring class skip or not?	100	0	2	1.80	.569	.323	-2.692	.241	5.716	.478
Response to Bullying	100	0	2	1.64	.542	.293	-1.166	.241	.382	.478
Reading Class Schedule 1	100	0	2	1.90	.362	.131	-3.899	.241	15.585	.478
Reading Class Schedule 2	100	0	2	1.94	.343	.118	-5.595	.241	29.898	.478
Reading Class Schedule 3	100	0	2	1.88	.477	.228	-3.762	.241	12.401	.478
Reading Class Schedule 4	100	0	2	1.96	.281	.079	-6.962	.241	47.418	.478
Reading Class Schedule 5	100	0	2	1.58	.819	.670	-1.446	.241	.092	.478
Cooking fire	100	0	2	1.54	.558	.312	-.694	.241	-.569	.478
Alarm, late for DocAppt	100	0	2	1.78	.484	.234	-2.154	.241	4.011	.478
Getting to Doc, bus	100	0	2	1.79	.574	.329	-2.594	.241	5.250	.478
No Driving, need dinner	100	0	2	1.13	.849	.720	-.253	.241	-1.572	.478
tornado warning	100	0	2	1.51	.772	.596	-1.177	.241	-.272	.478
Deep cut on finger	100	0	2	1.48	.643	.414	-.854	.241	-.310	.478
Late curfew, drinking	100	0	2	1.93	.326	.106	-4.994	.241	25.471	.478
Tumor, Doc advice	100	0	2	1.90	.414	.172	-4.172	.241	16.361	.478
Heart, Doc advice	100	0	2	1.74	.562	.316	-2.086	.241	3.326	.478
Assisted Living, Doc advice	100	0	2	1.27	.941	.886	-.569	.241	-1.647	.478
Teased about not drinking	100	0	2	1.77	.468	.219	-1.887	.241	2.828	.478
spend inheritance	100	0	2	1.43	.832	.692	-.955	.241	-.868	.478
Concert tix v Food	100	0	2	1.76	.534	.285	-2.184	.241	3.886	.478
Pay Power Bill or wait	100	0	2	1.82	.458	.210	-2.598	.241	6.286	.478
Special Event	100	0	2	1.77	.489	.239	-2.060	.241	3.576	.478
Grocery Store	100	0	2	1.28	.965	.931	-.592	.241	-1.683	.478
Bank acct Number	100	0	2	1.51	.835	.697	-1.202	.241	-.465	.478
Craigslist	100	0	2	1.59	.793	.628	-1.483	.241	.279	.478
Valid N (listwise)	100									

Note. Normal distributions have a skewness of zero and a kurtosis close to zero.

Cronbach's α for the Health and Safety Scale was .491. Cronbach's α for the Finances scale was .525 (all using the 22-item version of the instrument). It should be noted that these alpha estimates are likely to be an underestimate of the true alpha value for the CDMA-A because the computation assumes the data is continuous, when in fact, this data should be treated as ordinal.

Exploratory Factor Analysis

An Exploratory Factor Analysis (EFA) was attempted for the 28-item CDMA. The descriptive statistics for the 28 items of the CDMA indicate scores are not normally distributed. Six of the 28 items have a kurtosis higher than seven, well outside the typical range for kurtosis. The leptokurtic distribution implies the distribution will be tall instead of being normally distributed. In addition, 15 of the 28 items have a skewness outside of the normal range (+/-2). The negatively skewed distribution indicates that most of the participants earned the highest score on those 15 items. Although this is problematic for running the EFA, it is not unexpected for this population. A large amount of the participants in this study have never experienced a TBI and it would be assumed that a typically developing early adults do not have impaired capacity to make decisions. Thus, the negatively skewed data implies that a large portion of this sample has intact decision-making abilities. Unfortunately, the negatively skewed data limit the results of an EFA because of a lack of normal distribution and because the data should be treated as ordinal, not continuous which is not possible in SPSS.

A series of statistics (Kaiser-Meyer-Olkin, Bartlett's Test of Sphericity, Anti-Image, Measures of Sampling Adequacy) were conducted to determine whether the data set was factor analyzable. The Correlation Matrix shows extremely low correlations among items. Correlations below .30 are generally thought to be problematic. Correlations among the items range from .000 to .701, with only ten correlations being above .30. Problems with correlation among items may be due to the problems with normality. The Kaiser-Meyer-Olkin (KMO) is an indicator of the extent to which the factors reproduce correlation, with better reproduction signifying smaller unexplained variance. KMO compares the magnitudes between observed and partial correlation coefficients. The range for KMO is from 0-1, with KMO moving closer to one as correlations move closer to zero. The KMO for the CDMA is .57, which is classified as miserable based on Kaiser's proposed classification system (Kaiser, 1974). Bartlett's Test of Sphericity tests whether the correlation matrix is an identity matrix. The Bartlett's Test of Sphericity for the CDMA is statistically significant thus the correlation matrix is not an identity matrix.

Communalities represent how much of the variance in an item the factors can reproduce. Communalities can be a broad indicator of success in a factor analysis. Ideal communalities are .50 - .60 or higher, as higher communalities also indicate a smaller sample size being necessary for data analysis. The communalities for the items of the CDMA are in the acceptable level. The communalities range from .480 to .813. Only one communality was found to be in the unacceptable range (.480).

Each factor is also assigned an eigenvalue, which indicates the proportion of information that a given factor reproduces. Factors with eigenvalues greater than one explain more variance and are usually retained. The CDMA has eleven items with an eigenvalue greater than one. Those twelve items explain 67.272% of the variance. In addition, the scree plot uses eigenvalues to determine how many factors to extract. The scree plot for the CDMA indicates one factor should be extracted. The results from the eigenvalues and the scree plot are significantly different.

Based on the information presented previously (KMO, Bartlett's Test of Sphericity, Anti-Image, MSA), the data set from this study is not factor analyzable. Because of this, no other data could be gathered from the EFA of the CDMA. A factor matrix, pattern matrix, and structure matrix could not be computed for the data set. The EFA was hindered by the inability of SPSS to treat the data as ordinal instead of continuous and the lack of normal distribution in the sample. In addition, there are limited correlations between items and a restricted range of items scores. Factor analysis is not appropriate, given the lack of inter-item correlations.

Receiver Operating Characteristic (ROC) Curve Analysis

A ROC curve analysis was conducted in the R program to evaluate the ability of each item of the CDMA-A to distinguish between TBI and nonTBI participants. ROC Curves can be used to evaluate an instrument's ability to classify cases into groups correctly, (i.e. with and without TBI) by examining the trade-off between specificity (False Positive Fraction-FPF) and sensitivity (True Positive Fraction-TPF). A curve that bends toward the upper left corner of the graph indicates the instrument has greater discriminant capacity when categorizing cases. By contrast, a graph with a diagonal line indicates the instrument performs no better than chance when categorizing cases (Hijian-Tilaki, 2013). Below is the ROC Curves for the 22-item CDMA-A (see Figure 1). The Area Under Curve (AUC) is used as a general measure of predictive accuracy of the all the items combined (total score for 22 items) for whether the participant experienced a TBI. Most of the individual items fall within the range of fail on the of the ROC Curve, considering that an AUC of .50 is no better than chance. Items 17, 22, 28, and 29 all fall within the fair range on the scale. The graph in Figure 1 shows the AUC of all the items combined on the CDMA-A. The AUC of .88 (95% confidence interval: .76 to .99) is classified as "good," which speaks to the greater power of the CDMA-A when combining all the items together. See Appendix C for the script used to compute the AUC and confidence intervals in the R program.

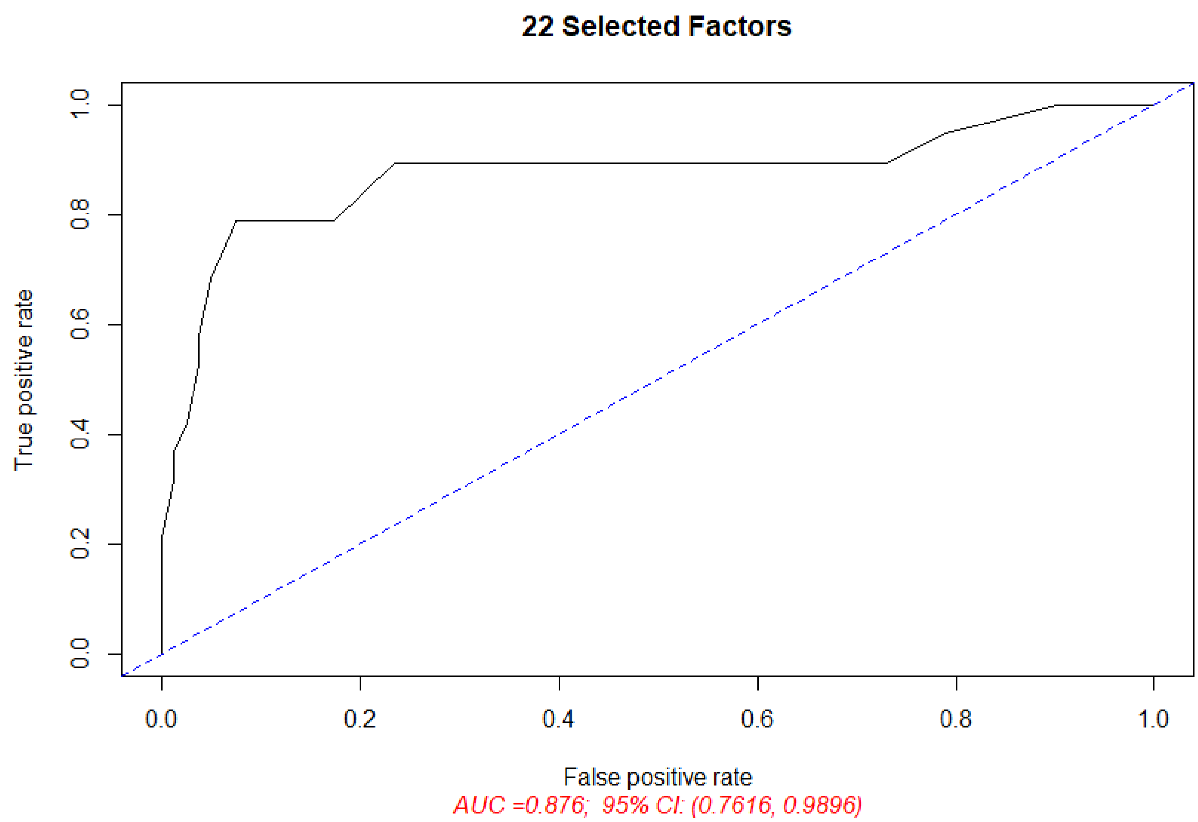

Figure 1. ROC Curves for CDMA-A All Items

Preliminary Analyses of Group Differences

Group differences on the WRAT Word Reading subtest were analyzed. Differences were noted between the TBI and nonTBI group using an independent samples *t*-test. There was a significant difference between the TBI (*M* = 86.53, *SD* = 14.05) and nonTBI participants (*M* = 107.77, *SD* = 10.90); *t*(98) = -7.22, *p* < .001 (two-tailed) with TBI participants scoring lower on the WRAT Word Reading subtest than those without a TBI. The magnitude of differences in the means (mean difference = -21.24, 95% CI: -27.08 to -15.40) was very large (Cohen's *d* = -1.69). There were no differences in scores based on sex with males (M = 102.91, SD = 15.59) and females (M = 104.70, SD = 12.51) not scoring significantly different *t*(98) = -.625, p = .533.

There were significant differences based on education where participants with high school education (*M* = 89.14, *SD* = 13.73) scored lower than those with college education (*M* = 107.61, *SD* = 11.64); *t*(98) = -6.22, *p* < .001. The magnitude of differences in the means (mean difference = -18.47, 95% CI: -24.36 to -12.57) was very large (Cohen's *d* = 1.45). Additionally, a one-way between-subjects ANOVA was conducted to compare the effect of ethnicity to the WRAT-WR score. There was not a significant effect [F (4, 95) = 1.58, p = .186, η^2 = .13].

An independent samples *t*-test was conducted to compare the CDMA-A scores for participants with and without a TBI. There was a significant difference between the nonTBI group (*M* = 38.42, *SD* = .402) and the TBI group (*M* = 30.00, *SD* = 5.61); *t*(98) = -8.14, *p* < .001 (two-tailed), with nonTBI participants scoring better on the CDMA than participants who had a TBI. The magnitude of differences in the means (mean difference = -8.42, 95% CI: -10.47 to -6.37) was very large (Cohen's *d* = 2.12).

Differences between sex of participants were also examined. An independent samples *t*-test was conducted to compare the CDMA-A scores for between males and females. There was a significant difference between males (*M* = 35.83, *SD* = 5.99) and females (*M* = 37.98, *SD* = 3.91); *t*(98) = -2.08, *p* = .040 (two-tailed) with female participants scoring higher than their male counterparts. The magnitude of differences in the means (mean difference = -2.15, 95% CI: -4.19 to -.10) was medium (Cohen's *d* = -.43).

There were also significant differences regarding education levels of participants. An independent samples *t*-test was conducted to compare the CDMA-A scores for between participants with high school versus college educations. There was a significant difference between participants with high school educations (*M* = 31.52, *SD* = 6.21) and participants with college educations (*M* = 38.23, *SD* = 3.91); *t*(98) = -6.10, *p* < .001 (two-tailed), with college educated participants scoring higher than those with a high school education. The magnitude of differences in the means (mean difference = -6.70, 95% CI: -8.88 to -4.53) was very large (Cohen's *d* = -1.29).

A one-way between-subjects ANOVA was conducted to compare the effect of severity of TBI to the overall CDMA-A score. There was not a significant effect of the severity of TBI to the overall CDMA-A score [F (2, 16) = 1.21, p = .323, η^2 = .13]. A one-way between-subjects ANOVA was conducted to compare the effect of months since TBI to overall CDMA-A score. There was not a significant effect of the months since TBI to the overall CDMA-A score [F (3, 15) = .97, p = .593, η^2 = .16]. There was a negative, but insignificant correlation between recovery time and score r(19) = -.22, p = .374. A one-way between-subjects ANOVA was also conducted to compare the effect of ethnicity to the overall CDMA-A score. There was not a significant effect of ethnicity on overall score [F (4, 95) = 1.58, p = .186, η^2 = .06].

Finally, the scores on the Self-Care Scale which were completed by both the participants who have experienced a TBI and their caregivers were compared. A paired-samples *t*-test was conducted to evaluate the differences among scores between participants and their caregivers. There was a statistically significant difference between scores where the TBI participants (M = 39.68, SD = 4.20) scored themselves higher on their ability to complete self-care tasks independently than did their caregivers (M = 32.47, SD = 4.14); t(18) = 8.55, p < .001 (two-tailed). The mean decrease in scores was 7.21 with a 95% confidence interval ranging from 5.44 to 8.98. The Cohen's *d* statistic (1.73) indicated a very large effect size.

Multiple Regression Model

Correlation and multiple regression analyses were conducted to investigate whether sex, severity of TBI, or recovery time (months since TBI) could significantly predict overall CMDA-

A score using the 22-item test. All 3 predictors were entered simultaneously. The multiple regression model with all three predictors produced $R^2 = .18$, $F(3, 15) = 1.13$, $p = .368$. Thus, the regression model explains 18% of the variance, but does not significantly predict overall CDMA-A score. Table 3 summarizes the analysis results. As can be seen, none of the three predictors significantly impact score on the CMDA-A. Of the three predictors, severity of TBI has the greatest impact on CDMA-A score (β = -.329).

Table 3

Correlations from Regression Analysis for Sex, Severity of TBI, and Recovery Time

Variable	β	*t*	Sig	Partial	Part
Constant		8.370	.000		
Sex	.210	8.98	.383	.226	.209
Severity of TBI	-.329	-1.337	.201	-.326	-.312
Recovery Time	-.108	-.440	.666	-.113	-.103

CHAPTER IV: DISCUSSION

Research has shown the difficulty in measuring decision making of patients who experience TBI. Tasks such as the *Iowa Gambling Task* offer a practical way to measure decision-making but fail to give real-world scenarios in which judgment decisions must be made. This study developed and tested a new instrument, *Capacity for Decision Making Assessment*, *Adolescent Version* (CDMA-A), on both nonTBI and TBI participants, with the purpose of assessing reliability and structural validity. I examined whether there was a difference in scores between nonTBI and TBI populations. I also examined whether there were sex differences in CDMA-A outcomes or differences among varying degrees of severity of TBI as well as time since TBI.

First, some evidence for the content validity of the new instrument was gleaned during the development process. Experts rated items on both the original 29-item CDMA-A and the corresponding 21 self-care questionnaire items. Raters were not told ahead of time which items were for the CDMA-A and which were for the self-care questionnaire. For all 51 questions, the Content Validity Index scores for all items were 1.00 using the ratings from both respondents, as both respondents were either somewhat, or very sure of their categorization of items and felt that all items were somewhat or highly relevant. Regarding the Factor Validation Index, the items received an FVI of 50%, which is below the desired FVI score, due to the respondents disagreeing on six items. This was often due to the respondents confusing items of self-care with items of health and safety. It is likely that if the respondents had been aware of the caregiver versus patient subtests, they may have been able to distinguish between the self-care and health and safety questions. Regarding qualitative feedback on the CDM-A, respondents noted that more questions focusing on peer interaction and behavioral situations in school would be helpful, as well as questions regarding issues of drugs and alcohol (i.e. risks involved, following the doctor's advice). Questions regarding these issues were added to the school and health and safety categories, respectively before it was administered to any participants.

Second, participant scores for each item of the original 29-item scale were examined, which revealed that one item had no response variance at all. Every participant scored the maximum points suggesting that item was not sensitive to rater variance. Third, internal consistency was measured for the remaining 28 items as an index of reliability. However, it only reached acceptable levels of reliability when six additional items were dropped, leaving a 22-item scale. Using the 22-item scale, various group differences were examined. Findings suggest that the CDMA-A was useful in distinguishing differences in scores between participants who have experienced a TBI and those who have not, with those experiencing a TBI earning lower scores. There were differences in decision making based on sex and grade level as well, with women and college educated participants scoring higher on the CDMA. Differences in scores due to education level should not be surprising as those participants are older, usually with more experience living independently, further brain development, and more developed abstract reasoning than less educated peers. Similarly, scores on the WRAT Word Reading subtests also showed that participants with college educations had higher word reading skills, again presumably due to greater experience with reading and vocabulary as a function of their education. There were no significant differences found in scores based on severity of TBI, or time since experiencing a TBI; however, this may have been due to the small sample size of participants with a TBI. There were significant differences when comparing the scores on the self-care questionnaire between the participant and their caregiver. This suggests a lack of insight by the participants regarding their ability to perform daily living tasks after experiencing a TBI.

The caregivers noted the participants needed much more assistance performing these tasks than the participants reported.

Unfortunately, the data did not permit an exploratory factor analysis, but I did subsequently test the predictive accuracy of the CDMA-A. During the EFA, many items were negatively skewed, which again may be a result of not having a larger sample size of participants who experienced a TBI. While the Eigenvalues and Cronbach's α did not support the idea of the three separate subtests within the CDMA-A, the alpha when combining all items for the total score was acceptable. Similarly, according to the ROC Curves, the individual items showed poor predictive qualities aside from four items in the fair range. However, the predictive accuracy for identifying a TBI when combining all items was much stronger.

Finally, regression models were not successful in demonstrating that variables such as sex, severity of TBI, and time since experiencing a TBI were able to predict scores on the CDMA-A. Though none of the three variables were significant, the severity of the TBI appeared to have the strongest unique contribution to explaining the overall score. Unfortunately, the model only explained approximately 21% of the variance in the CDMA-A scores.

Perhaps, the results above explain why quality assessments of real-life judgment and decision-making are difficult to find. Although an EFA was not able to be performed on the data gathered from this sample, meaningful findings can still be gleaned. Though the population of participants with a history of TBI was small in comparison to the overall sample, there were significant differences between participants with previous TBI and those without. Participants with no previous history of TBI scored higher than participants who have experienced a TBI in the past. This finding is in line with previous research on decision-making ability of patients with a TBI. Decision making in these patients has been shown to be impaired. Significant differences were not found among severity of TBI or time since TBI, but this could be due to the small sample sizes for each group.

Limitations and Directions for Future Research

There are several limitations to the current study involving sample and methods. First, data analysis would have benefitted from a larger population of participants, specifically more participants who have experienced a TBI. However, because this is a protected population, it was extremely difficult to recruit participants who have previously experienced a TBI.

Several public-school districts would not allow data collection through the schools. Some private practice offices allowed for a flyer to be placed in the waiting areas; however, this led to very little recruitment. Of the participants who have experienced a TBI, most experienced a mild TBI. Thus, there was not a great deal of variance in the severity of TBI, which may have minimized the strength of the results. A larger group of participants with TBI may have normalized the data, so that more statistically significant findings could be detected. Additionally, for the undergraduates who were recruited, the participants volunteered for the study to earn points for a class. Points were given based on completion of the assessment, not quality of answers. Thus, participants may not have taken the assessment seriously because no meaningful grade was being given based on effort, which could lead to lower scores on the protocols for non-TBI population than would be expected. For example, if the highest score to obtain is a 56 and the highest score obtained by nonTBI participants was 50, this could be due to lack of effort as opposed to poor decision-making skills.

Overall, these are limitations that can be improved upon with further research on this instrument. A larger and more diverse sample may improve the data on this instrument and the chances to run an appropriate EFA on this instrument. If the statistics are not improved with a larger sample size, the item construction would have to be revised to better assess for decision making capabilities. Once this can be achieved, additional data can be collected and analyzed to improve this instrument for possible clinical use. As seen from the research discussed above, an instrument such as this one can be extremely beneficial in assessing the decision-making skills of post-TBI patients.

Regarding future research for the CDMA, replication of the findings above would enhance the utility of the CDMA, especially if further studies include larger samples sizes with more variability in recovery time and severity of TBI and more significant results. It would be worthwhile to attempt another content validity study with better response rates from content validity experts. Perhaps offering incentive to the experts would improve response rates. Additionally, future studies which compare the CDMA with other established decision-making instruments could provide valuable information regarding the validity and reliability of the instrument. It would also be interesting and worthwhile to look at the predictive validity of the CDMA, perhaps by examining the correlations between scores on the CDMA and whether or not the participant is ruled as incompetent by court, or whether not they are able to successfully live independently after a 6-12 month follow-up.

Conclusion

This study describes the development and initial psychometric analyses of a new instrument, called the *Capacity for Decision Making Assessment, Adolescent Version* (CDMA-A). Although there were difficulties concerning the sample size and ability to perform an EFA on the instrument, the data shows that the CDMA-A was successful in distinguishing between the scores of participants who have experienced a TBI and those who have not. It also highlighted differences in the perception of ability to perform daily living tasks between participants who have experienced a TBI and their caregivers, which suggests difficulties in insight stemming from experiencing a TBI. Awareness of this lack of insight could be useful when treating patients who have experienced a TBI and when assessing for their ability to live independently and remain their own guardians. Future research and large sample sizes may also allow for differences among severity of TBI and time since experiencing a TBI to be garnered, which could assist more in treatment concerns and accommodations for those who have experienced a TBI.

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APPENDIX A

Capacity for Decision Making Assessment - Adolescent Version

Please read each scenario to the examinee and record their response. Award points based on their responses using the examples given below each scenario.

SCHOOL/VOCATIONAL

Problem 1: You realize when you wake up in the morning that you forgot to complete a homework assignment for your second period class. What should you do?

Answer: Skip your first class and complete the homework assignment (1). Show up to class and admit you did not do your homework (2). Try and complete your homework while in your first period class (1). Copy someone else's homework between classes (0). Talk to your teacher before class and ask if you can hand in the assignment late for partial credit (2).

Problem 2: You are with a group of friends and say something that offends another person in the group. What should you do?

Answer: Apologize for offending the other person (2) Become upset that you hurt someone feelings (i.e. cry) (1) Worry for the rest of the day about offending someone (1) Ignore that you offended someone. They will get over it. (0) Become angry at that person for being offended. (0)

Problem 3: You have two tests next week, on Wednesday and Thursday. Your friends want to go to the beach for the weekend, but you need to study for both tests at some point as well. What should you do?

Answer: Skip the beach and study this weekend and up until the tests dates (2). Go to the beach and start studying Monday (1). Study the night before each test (1). Don't study for either test (0).

Problem 4: You do not like your teacher in first period and think her history class is boring and useless. You need to pass the class to graduate and attendance is part of your grade. You would much rather act like you are sick so that you can go into the nurse's room instead of going to class. What should you do?

Answer: Go to class anyway (2). Go to class and sleep through it (1). Fake sick and go to the nurses' room (0). Just skip the class altogether (0).

Problem 5: You see a smaller child being bullied in the bathroom by a larger child in the bathroom. You are the only one who is there. What should you do?

Answer: Tell an adult immediately (2). Try to intervene (1). Leave and say nothing (0).

Problem 6: Your best friend just told you he/she found out her significant other was cheating on him/her with another person at school. How do you expect your friend feels?

Answer: Sad, mad, angry, shocked, disappointed (or any variation of these emotions) (2). Any other emotion (0).

Using the following class schedule answer the questions below:

Class	Time	Days	Where	Date Range	Schedule Type	Instructors
Intro to Psychology	11:30 am - 2:00 pm	M	Bear 230	Aug 20, 2013 - Dec 13, 2013	Lecture	Dr. Cone
Math	4:00 pm - 5:15 pm	TR	Rawl Building 342	Aug 20, 2013 - Dec 13, 2013	Lecture	Dr. John
English	3:00 pm - 4:00 pm	W	Rawl Building 205	Aug 20, 2013 - Dec 13, 2013	Seminar	Dr. Taper
Biology	9:30 am - 12:00 pm	W	Ragsdale Hall 130	Aug 20, 2013 - Dec 13, 2013	Lecture	Dr. Green

7) What class(es) do you have on Wednesday?

8) Who teaches your Biology class?

9) What is the first day of classes?

10) Where is your Math class located?

11) How long is your Biology class?

HEALTH & SAFETY

Problem 12: You are cooking at home alone and a fire starts on the stove. What is the first thing you should do?

Answer: 2 points—Call 911 (then get out of the house), Use a fire extinguisher. 1 point—Run and get a neighbor. 0 points—I don't know. Leave the house without ever calling 911.

Problem 13: Your alarm does not go off in the morning and you wake up realizing you will be 30 minutes late to a doctor's appointment. What should you do in this situation?

Answer: A 2-point answer would be to call and say you are going to be late, but still go to the appointment, or reschedule if they request that. A 1-point answer may be to just leave and show up late without calling ahead. A 0-point answer would be to just skip the appointment.

Problem 14: Your medication needs to be refilled, but you need to see your doctor before you can refill it. You have to take the bus to see the doctor and you don't like the crowded buses. There is no one else to take you to the doctor. What should you do?

Answer: Make an appointment to see the doctor and use the bus, despite your dislike because your medication is important (2). Don't worry about refilling your medication (0). You don't need medication anyway (0).

Problem 15: Your doctor has not cleared you to drive yet, but you are home alone and have nothing to eat for dinner. No one is available to come and get you or bring you anything for another 3 hours. Your car is in the garage and you know where the keys are placed. The nearest store/restaurant is a 5-minute drive away. What should you do?

Answer: Wait for someone to come and take you to eat (or bring you something to eat) (2). Order delivery (2). Try to walk to the store/restaurant (1). Get in the car anyway because the store/restaurant is close (0).

Problem 16: You are watching television and a tornado warning for your area comes onto the screen. What should you do?

Answer: Take cover in a room with no windows/cellar/safe place (2). Ignore the warning (0).

Problem 17: You are cutting an apple and you cut your finger. The cut is deep and there is a lot of blood. What should you do?

Answer: Seek medical care (2). Call someone for help (1). Put on a Band-Aid (0). Wrap it in cloth/paper towels (1).

Problem 18: You are at a party at a friend's house and have to be home by 11pm because of your curfew. It is 10:50 and you have had too much alcohol to drive home. You live several miles from this home, and it is a 15-minute car ride to your house. Your friend says he will take you home in 10 minutes, but then you will be late. What should you do?

Answer: Have a sober friend drive you home (2). Call a cab (2). Call your parents (2). Walk home (0). Drive myself home (0). Basic point is to be late instead of trying to get home in a hurry and driving yourself.

Problem 19: The doctors report you have a tumor that should be removed. It is not causing any problems at this time, but the doctors say it may grow larger and could cause problems in the future. You are at a higher risk for the tumor to cause problems because of a previous brain injury. What should you do?

Answer: Follow the doctors' advice to have the tumor removed (2). Wait and see if it grows larger (1). Refuse to have the tumor removed (0).

Problem 20: You have an irregular heartbeat and have been in the emergency room several times because of a heart murmur. Your doctor advises you to have a pacemaker placed in your heart to regulate the heartbeat. You are afraid of surgery and hospitals. What should you do?

Answer: Have the pacemaker put in (2). Consult with family and other medical professionals (2) Refuse to have the pacemaker put in (0).

Problem 21: You are living at an assisted living facility after experiencing a traumatic brain injury. You don't like following their rules and want to live in your own apartment, like you did before. You have money for an apartment, but your family and doctor think you should stay in the assisted living facility. What should you do?

Answer: Leave the facility and find your own place (0). Stay in the facility (2). Try to find another facility you like better (1).

Problem 22: Your doctor tells you that drinking alcohol can be dangerous for you, especially after experiencing a brain injury. You are invited to a party and your friends are all laughing at you because you said you could not drink alcohol. They are calling you names and say they will stop if you drink some alcohol. What should you do?

Answer: Not drink any alcohol or leave the party (2). Just have one sip/drink (1). Drink as much as you want (0).

FINANCIAL

Problem 23: You inherit $30,000 from a family member and can do whatever you want with that money. What would you do with the money?

Answer: Put all of the money in the bank to save for the future. (2) Save most of the money but spend a small portion. (2) Pay off my debts. (2) Spend most of the money but save a small portion. (1) Give the money to charity. (1) Spend all the money on whatever I want (i.e. if they say buy a car, go on a trip, etc.). (0)

Problem 24: You have $30 to last you from Wednesday to Friday that is allocated for food and drinks. Concert tickets go on sale for a group you have been waiting to see and you know the tickets will sell out before Friday. You do not own a credit card. What should you do?

Answer: Use the money for food like it is allocated, so you can eat for the rest of the week. (2) Borrow the money for concert tickets from someone else. (1) Buy the concert tickets and worry about money for food later. (0)

Problem 25: Your power bill is due. If you pay it now you will have $150 to last you until you get paid in two weeks. If you wait two weeks to pay it, they will turn your power off. Your credit card is maxed out. What should you do?

Answer: Pay the bill and budget for the next two weeks with your $150 (2). Borrow money to pay your power bill (1). Wait until pay day to pay your power bill (0).

Problem 26: You want to attend a special event in two months that costs $50. You get an allowance of $10 a week. What would you do?

Answer: Save the money for 5 weeks so you'll have enough to attend (2). Worry about it when it is closer (0). Borrow the money to attend the event (1).

Problem 27: You have $5.25 to spend at a grocery store. You want to buy a drink and a bag of chips. The drink is $1.25, and the chips are $1.30. How much money will you get back in change?

Answer: $2.45

Problem 28: You get a phone call asking you to complete a survey, for which you will receive $50 for your participation. After the survey, the interviewer asks for your bank account number in order to deposit your $50. What should you do?

Answer: Not give out your bank account number (2). Find out more information (1). Give them your bank account number (0).

Problem 29: You are selling an item on Craigslist and a buyer contacts you wanting the item. He states he will send a check in the mail once he receives the item. What should you do?

Answer: Do not send the item (2). Ask for payment up front (2). Send the item and wait for the check (0).

SELF-CARE (One to be completed by respondent and one completed by caregiver)
Check the appropriate box for what the respondent is able to do *most* of the time:

Task	With Full Assistance	With Some Assistance	With No Assistance
1. Can the person dress himself/herself?			
2. Can the person shower?			
3. Can the person use the bathroom?			
4. Can the person get up using an alarm?			
5. Can the person ambulate?			
6. a) If the person uses a wheelchair (w/c): b) Can the person transfer from w/c to bed?			
c) Can the person transfer from w/c to car?			
d) Can the person transfer from bed to w/c?			
e) Can the person transfer from car to w/c?			
7. Can the person do light housekeeping tasks such as washing dishes or making their bed?			
8. Can the person do heavy housekeeping like mopping or vacuuming?			
9. Can the person do their laundry independently?			
10. Can the person fix microwaveable meals?			
11. Can the person prepare meals on a stove/in an oven?			
12. Can the person follow a restricted diet?			
13. Can the person take their medication as prescribed?			
14. Can the person drive an automobile?			
15. Can the person take public transportation?			
16. Can the person do their own shopping?			
17. Can the person manage a budget?			
18. Can the person pay their own bills?			
19. Can the person operate a telephone?			

APPENDIX B

IRB APPROVAL LETTER

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building · Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** ·
www.ecu.edu/ORIC/irb

Notification of Continuing Review Approval: Expedited

From: Social/Behavioral IRB
To: Holly Manley
CC:
Christy Walcott
Date: 11/20/2017
Re: CR00006463
UMCIRB 16-000631
Decision making for TBI and nonTBI persons

The continuing review of your expedited study was approved. Approval of the study and any consent form(s) is for the period of 11/20/2017 to 11/19/2018. This research study is eligible for review under expedited category #7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Document	Description
Assent for ages 12-17 ECU.doc(0.01)	Consent Forms
Assent for ages 12-17 MPPA.doc(0.01)	Consent Forms
Assent for ages 12-17 SRMC.doc(0.01)	Consent Forms
Assent for ages 12-17 wayne county.doc(0.01)	Consent Forms
Assent for ages 12-17.doc(0.01)	Consent Forms
Assent Form Cherry Hospital.docx(0.01)	Consent Forms
Consent Form Cherry Hospital.docx(0.01)	Consent Forms
Consent form ECU.doc(0.01)	Consent Forms
Consent form MPPA.doc(0.01)	Consent Forms
Consent form SRMC.doc(0.01)	Consent Forms
Consent form wayne county.doc(0.01)	Consent Forms
Consent form.doc(0.01)	Consent Forms
Holly Dissertation Proposal Final.docx(0.01)	Study Protocol or Grant Application
Interview Demographics for adult.doc(0.01)	Surveys and Questionnaires
Interview For Parent-Guardian and Demographics.doc(0.01)	Surveys and Questionnaires
research study flier.doc(0.01)	Recruitment Documents/Scripts

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX C

R SCRIPT FOR ROC CURVE ANALYSIS

```
library(foreign)

HollyRData <- read.spss("HollyDataDiss.sav")

#Vector of Column Variables
colvars = names(HollyRData)

#ID Starting Variable
start_loc = match("P1",colvars)

#ID Ending Variable
end_loc = match("P29",colvars)

#Subset Prediciton Variables of Interest
test = data.frame(HollyRData[start_loc:end_loc])

library(ROCR)
library(pROC)
#Loop Through Predictors and Plot ROC Curves for Each Against
TBI
opar <- par(mfrow=c(1,1))
par(mfrow=c(3,2))
for (i in 1:29) {
x <- abs(test[i]-2) #invert scores so that higher score
indicates TBI
pred <- prediction(x,as.numeric(HollyRData$TBI)-1) #'as.numeric'
and '-1' convert from levels of 1/2 to binary 0/1
perf <- performance(pred,"tpr","fpr")
auc <- performance(pred, "auc")
auc <- round(auc@y.values[[1]],3)
plot(perf)
title(main=paste("Predictor", i), sub=paste("AUC =", auc),
col.sub="red", font.sub=3)
abline(a=0,b=1,col="blue",lty=2)
}

par(opar)
#Plot ROC curve for total score on all 29 parameters
pTot <- rowSums(abs(test-2)) #58 is max possible score;
inverting so that higher score indicates TBI
pred <- prediction(pTot,as.numeric(HollyRData$TBI)-1)
perf <- performance(pred,"tpr","fpr")
```

```
auc <- performance(pred, "auc")
auc <- round(auc@y.values[[1]],3)
roc_stat_29 <- roc(as.numeric(HollyRData$TBI)-1,pTot)
roc_ci_29 <- ci(roc_stat_29)
plot(perf)
title(main=paste("All Factors"), sub=paste0("AUC =", auc, "; 95%
CI: (", round(roc_ci_29[1],4), ", ", round(roc_ci_29[3],4),
")"), col.sub="red", font.sub=3)
abline(a=0,b=1,col="blue",lty=2)

#Plot ROC curve for total score on 22 selected parameters
#Eliminated variables P1, P3, P5, P6, P16, P20, P24
test22 <- test[,c(2,4,7:15,17:19,21:23,25:29)]
pTot <- rowSums(abs(test22-2)) #inverting so that higher score
indicates TBI
pred <- prediction(pTot,as.numeric(HollyRData$TBI)-1)
perf <- performance(pred,"tpr","fpr")
auc <- performance(pred, "auc")
auc <- round(auc@y.values[[1]],3)
roc_stat_22 <- roc(as.numeric(HollyRData$TBI)-1,pTot)
roc_ci_22 <- ci(roc_stat_22)
plot(perf)
title(main=paste("22 Selected Factors"), sub=paste0("AUC =",
auc, "; 95% CI: (", round(roc_ci_22[1],4), ", ",
round(roc_ci_22[3],4), ")"), col.sub="red", font.sub=3)
abline(a=0,b=1,col="blue",lty=2)

#Plot ROC curve for total score on 18 selected parameters
#Eliminated variables P1, P3, P5, P6, P16, P20, P24
test22 <- test[,c(2,4,7,9,11:15,17,21:23,25:29)]
pTot <- rowSums(abs(test22-2)) #inverting so that higher score
indicates TBI
pred <- prediction(pTot,as.numeric(HollyRData$TBI)-1)
perf <- performance(pred,"tpr","fpr")
auc <- performance(pred, "auc")
auc <- round(auc@y.values[[1]],3)
roc_stat_18 <- roc(as.numeric(HollyRData$TBI)-1,pTot)
roc_ci_18 <- ci(roc_stat_18)
plot(perf)
title(main=paste("18 Selected Factors"), sub=paste0("AUC =",
auc, "; 95% CI: (", round(roc_ci_18[1],4), ", ",
round(roc_ci_18[3],4), ")"), col.sub="red", font.sub=3)
abline(a=0,b=1,col="blue",lty=2)
```