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THE ROLE OF AWARENESS IN TRAUMATIC BRAIN INJURIES: INTERVIEWS WITH
EXPERTS

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Abstract

Approximately 2.8 million US citizens sustain a traumatic brain injury (TBI) annually, with more than 275,000 requiring inpatient rehabilitation (Taylor, Bell & Breiding, 2013). As rehabilitation techniques are refined and adapted to increase the speed of recovery and functional independence following TBIs, there is an ongoing need for better prognostic assessment tools. Research has shown that a lack of self-awareness following TBI is associated with poorer outcomes (e.g. employability, community reintegration) following discharge from inpatient hospitalizations (Cheng & Man, 2006; Robertson & Schmitter, 2016) and can result in decreased motivation (Simmonds & Fleming, 2003), compromised safety, poor community re-integration, and impaired judgment (Hart & Sherer, 2009).

The paucity of empirical and objective measurements for a factor strongly correlated with rehabilitative success and prognosis and the lack of consensus about the nature of self-awareness, suggest a need for additional work to develop measures of awareness. Semi-structured interviews were conducted with experts in the field who provided information on their current practices, limitations, and aspirations for the assessment of awareness in those with traumatic brain injuries. Interviews were coded to aid the creation of a universal definition of self-awareness and the development of a meaningful and utilitarian assessment, as well as to identify future directions for the treatment of those with self-awareness deficits following traumatic brain injury. In summary, experts believe awareness should be defined based on the individual's level of consciousness, awareness of functional limitations, and insight shown. If further assessment is required, experts proposed an approach that engages patients in pre and post-test reflection of their ability to complete a performative task. The discrepancy between their actual performance and their awareness of their performance could be quantified and used to measure current level

of self-awareness and improvement over time. This assessment approach could help provide a quantitative measure of treatment efficaciousness.

Keywords: traumatic brain injuries (TBIs), awareness, assessment, rehabilitation

The Role of Awareness in Traumatic Brain Injuries: Interviews with Experts

Introduction

Impaired awareness is a common problem in individuals who suffer a TBI (Sherer et.al, 1998; Kelley et.al, 2013) and can result in decreased motivation (Simmonds & Fleming, 2003), compromised safety, poor community re-integration, and impaired judgment (Hart & Sherer, 2009). Furthermore, it is thought that without the ability to recognize one's deficits, an individual is less likely to benefit from rehabilitative treatments if the awareness deficit is not addressed first (Goverover et.al, 2007). Studies have also found that those with awareness deficits will more effectively benefit from rehabilitation efforts that focus on task-specific learning and habit formation (Callagan, Powell & Oyebode, 2006). Some researchers believe that developing self-awareness requires the integration of thoughts and feelings (Fleming & Strong, 2016), while others simply recognize the need for practical guidelines grounded in research and theory to be established (Fernandez-Espejo & Owen, 2013). Thus, the ability to determine a patient's level of self-awareness in the first place carries multiple implications for effective rehabilitative treatment and future prognosis. Nevertheless, the field lacks consensus on a clear definition for awareness as well as how to best rehabilitate awareness deficits. A review of the literature shows, there are only three measures of awareness available for clinicians at this time: The Self-Awareness Deficit Interview, the Awareness Questionnaire, and the Patient Competency Rating Scale (Fleming et.al., 1996; Sherer, 2004; Prigatano, 1986). The following study aims to better understand the ways in which experts have operationalized and assessed for awareness deficits, as well as their current practices for rehabilitation. The study hopes to provide a foundation for a new shared definition of awareness in the form of a new tool that providers can use to assess level of awareness following a TBI.

Traumatic Brain Injury. Traumatic Brain Injury (TBI) is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force (Menon, et.al, 2010). Alteration in brain functioning is identified by the presence of one of the following symptoms:

- Any period of decreased or loss of consciousness caused by brain injury
- Any loss of memory for events immediately before (retrograde amnesia) or after the injury, known as post-traumatic amnesia (PTA)
- Neurologic deficits (weakness, loss of balance, change in vision, dyspraxia paresis/plegia [paralysis], sensory loss, aphasia, etc.)
- Any alteration in mental state at the time of the injury (confusion, disorientation, slowed thinking, etc.)

TBI's are then further classified into ranges of severity which include: Mild, Moderate, and Severe. Such classifications are typically determined by three factors. The duration for which there is a decrease or loss of consciousness, the duration of memory lapse and the Glasgow Coma Scale (GCS). The GCS measures an individual's functioning in three areas and is completed by health care providers as soon as possible following injury. The GCS requires the rater to determine a total score that is based on the individual's ability to speak, open their eyes when asked and ability to voluntarily move. A higher GCS score indicates a lower severity of injury, with a possible score range of zero to fifteen. The following table provides a break-down of the different severity ranges under which TBI's are commonly categorized, as well as the most common ratings.

TBI Severity	Loss of Consciousness	Memory Gap	GCS Scale
Mild	< 30 mins	< 24 hrs.	13-15
Moderate	30 mins to 24 hrs.	1 to 7 days	9-12
Severe	> 24 hrs.	> 7 days	3-8

(Meyer, K. & Jaffee, M., 2013)

While classification provides medical providers with pertinent information about the severity of injury, severity does not always correlate with functional impairment nor prognosis. Location of injury, nature of injury, premorbid and postmorbid health concerns, age, and psychosocial factors also serve contributory roles in functional impairment and rehabilitation (Baalen et.al, 2003). While the degree of impairment of self-awareness has been found to vary across the spectrum of injury severity (Godfrey et.al, 2003), the prevalence of impaired self-awareness in TBI's was found to be between 76 and 90% (Sherer et.al, 1998) with an overall positive correlation between severity of functional impairment and severity of impaired self-awareness (Dirette, Plasier & Jones, 2008).

Impaired Self-Awareness. Impaired self-awareness has been defined in many ways, including “the inability to recognize deficits resulting from the neurological injury or the inability to recognize the functional implications of the deficits and set realistic goals” (Toglia & Kirk, 2000), “the ability to be aware of one’s own thoughts, feelings and mental states” (Keenan, Gallup & Falk, 2003), the “difficulty in the appraisal of their strengths and weaknesses and the implications of the changes that result from the TBI for life in the present and future” (Fleming, Strong, & Ashton, 1996), and “the over or underestimation of competencies” (Smeets et al.,

2014). Prigatano's (1999) research found that patients with impaired self-awareness lacked information about themselves, experienced cognitive confusion when they are receiving feedback about their behavioral limitations and expressed a cautious willingness or indifference when asked to consider information about their functional challenges. He differentiated between anosognosia (i.e., awareness deficits resulting from brain tissue damage visible on imaging) and psychological impairment in self-awareness in the absence of imaging. Up to 45% of those recovering from mild-to-moderate traumatic brain injuries were found to have deficits in psychological self-awareness (Gremley, 2006). Poorer awareness following TBI can result in decreased motivation, compromised safety, poor community re-integration, impaired judgment, and the ability to learn and retain procedural memory of activities of daily functioning (Simmonds & Fleming, 2003; Hart, & Sherer, 2009; Gremley, 2006). Without the ability to recognize one's deficits, an individual is less likely to benefit from rehabilitative treatments if the awareness deficit is not addressed first (Goverover et al., 2007). Espejo & Owen (2013) concluded that the lack of a universal definition prevents providers from effectively assessing and treating self-awareness and noted the need for practical guidelines based in research and theory to be established in order for the field to progress.

Study Rationale

While research confirms the significant role of self-awareness in effective recovery from TBIs, the definition, assessment measures, and rehabilitative interventions for self-awareness is marked in its absence and ambiguity. The following qualitative research is designed to gather information from experts in the field to construct a shared definition of awareness, which will facilitate the development of a valid, reliable and efficacious awareness measure. Research has shown that talking to experts in the exploratory phase of creating a consensus in a field is a more

efficient and concentrated method of gathering data (Hailingberg, et.al., 2018). Conducting expert interviews can serve to shorten time-consuming data gathering processes, particularly if the experts are identified as “crystallization points” for practical insider knowledge and are interviewed as surrogates for a wider circle of players (Collins & Evans, 2002). In this study, experts were identified as “crystallization points” and perceived to be surrogates for the wider field.

Methodology

In order to serve as an expert, the psychologist must have worked with TBIs for a minimum of ten years and be board certified in rehabilitation psychology. Nine identified experts completed a semi-structured interview that asked about their definition of awareness following TBI, current method of assessing awareness after TBI, and treatment practices for TBI involving awareness deficits. Interviews were then transcribed and analyzed multiple times by the researcher and two graduate student peers to identify common themes across responses. Themes were further subdivided into categories and subcategories. Data gathered is intended to serve as the basis of a shared definition of self-awareness, future inclusion criteria for an awareness measure, and treatment guidance.

Participant Description

Prior to recruitment of participants, this study was approved by the University of Denver Institutional Review Board in August 2019. Participants were then recruited from Craig Hospital, a specialty traumatic brain injury and spinal cord injury hospital, and the Rocky Mountain Regional Veteran Affairs Health Care System’s neuropsychology and inpatient rehabilitation departments. Eligible participants had to be board certified clinical psychologists in rehabilitation psychology and to have worked with traumatic brain injuries in an assessment and/or

rehabilitative role for a minimum of ten years. A total of nine participants volunteered and were interviewed for a duration of 45 minutes to an hour each. Participants were provided written informed consent of the nature of the study, the study's purpose, and of the time commitment (no more than one hour) that participation in the study entailed. Verbal consent was also received for the recording of sessions to allow for accurate transcription and analysis. Potential harm to participants was described as minimal, and participants were informed that they were not required to answer any questions with which they were uncomfortable. They were also informed that they could discontinue the interview at any time. The researcher had varying degrees of existing professional relationships with each expert, ranging from supervision relationships to limited familiarity via American Psychological Association Division 22 conferences. All participants denied concern about this dual relationship and each volunteered willingly and without compensation.

Results

The results are presented in order of the semi-structured interview questions and organized by the frequency with which the particular category of response occurred. Each resulting category includes a descriptive analysis of the theme and specific statements from participants. Results are presented in table format in Appendixes 1 through 5.

Defining Awareness

Consciousness. Experts agreed that emergence from Post-Traumatic Amnesia (PTA) was a condition for awareness. PTA is a state of confusion that occurs immediately following a TBI in which the injured person is disoriented and unable to remember events that occur after the injury. The person may be unable to state their name, where they are, and what time it is. Experts agreed that a patient needs to have sufficient arousal and be alert for a long enough period to be

able to experience awareness. The “gold standard” measurement of consciousness in TBI rehabilitation is the Rancho Los Amigos Scale (RLAS) (Lin, 2019). The RLAS of Cognitive Functioning is a medical scale used to measure and identify the recovery pattern of the cognitive level and behavioral changes observed. There are 8 levels of consciousness and experts agreed that a patient required at least an RLAS level 6 to have awareness. It is at a level 6 during which a patient is conscious enough to be able to demonstrate awareness of self, situation, and environment but unaware of specific impairments and safety concerns. Experts interviewed agreed that an RLAS 6 is the minimum requirement of consciousness necessary for awareness to exist. Once a patient is at this level, their understanding of the injury and its implications can be accurately assessed.

Accurate Knowledge of Functioning and Abilities. Experts defined awareness as an individual’s ability to accurately assess their level of functioning and abilities post injury. One expert defined it as “An individual’s ability to accurately assess their own abilities, their own way of being in the world, and their current functioning” while another extrapolated on this same idea and defined it as the “strengths and weaknesses.” Furthermore, the greater the discrepancies in self-perceived abilities and actual abilities, the larger the deficit in self-awareness was determined to be. Another expert also noted that, “with the right cognitive capacity a person can have awareness of a deficit, but they may not agree with it. They don’t have insight but they’re aware that this bothers their family.” This suggests that an individual’s ability to consider the perspectives of others even if those differed from their own, was considered evidence of awareness.

Insight. All experts brought up the topic of insight. Two primary categories of thinking arose when experts were asked to relate insight to awareness: Insight as separate from awareness

and insight as a measure of one's awareness. One participant differentiated between the two in this way, "Insight feels more retrospective than awareness which feels more present. Insight is an accumulation of awareness-evoking experiences", while another stated that, "Insight gets built based on a collection of evidence. Insight is somebody being aware based on past experience that this is something they can't do. It's an accumulation of information over time versus awareness is in the moment." This suggests that insight is an accumulation of awareness building experiences. Awareness was thought to be a state of being, whereas insight was a trait that resulted from the accumulation of awareness evoking moments. Therefore, a lack of insight suggested to experts that an individual lacked awareness into their functional abilities.

Impact of Awareness on Treatment

Treatment Engagement. Experts were unanimous in their agreement that a lack of awareness negatively affected treatment engagement. This was evidenced by statements such as, "a lack of awareness is highly detrimental to treatment engagement." Experts shared that a patient who was unaware of their injury and its implications were less motivated to engage in treatment. Patients who do not believe they have any problems, do not want to engage in rehabilitative treatment. One expert described a patient who lacked awareness and who wanted to leave against medical advice (AMA). The patient's lack of awareness meant they lacked capacity to leave AMA resulting in high levels of conflict between the patient and their team. Thus, a lack of awareness can influence a team's determination of medical decisional capacity, which carries significant implications for providers and treatment engagement.

Prognostic Factors. Experts agreed with the literature that a lack of awareness was related to poorer prognosis. A lack of awareness correlated with a lack of treatment engagement, as well as an unwillingness of the patient to acknowledge the wider implications of their injury.

One expert stated, “if you cannot see your own role within the recovery process, you cannot see how your behavior and engagement may affect that outcome.” The time taken to gain awareness (assuming the team was able to treat the awareness deficit), resulted in delayed rehabilitation and fewer interventions during the first 6 months post-injury, which is considered to be the prime TBI recovery period.

Misattribution. Prognostic factors further involved misattributions made by the team and family about the patient’s lack of awareness. In other words, team members and family believed that the patient was volitionally denying their injury or consciously rejecting treatment. These misattributions were described as harmful in that they affected the patient’s support system and reduced the desire of other people to help the person. An expert expressed that a lack of awareness, “hurts their support system. People do not want to work with them because it’s frustrating for the family and the team.”

Increased Safety Risks. Experts reflected that a patient lacking in awareness posed greater safety risks to themselves and to those around them both while in the hospital and in the community. Within the hospital, the patient’s unwillingness to follow safety procedures increased their risk of personal secondary injuries (e.g., falls, cerebral infarction, infection, malnutrition), and the risk of injury to those working with them. For example, a physical therapist may be bracing a patient to transfer them, but if the patient does not follow the appropriate steps, the physical therapist also risks injury. In the community, a patient who lacks awareness can pose significant harm to themselves and those in their community. For example, a patient who lacks awareness may attempt to drive a car with motor deficits or slowed processing speed.

Assessing Awareness

Observation. Experts were aware of the presence of standardized awareness measures but did not find them useful. The most common reasons cited were poor utility for their specific settings, and challenges maintaining strict standardization with protocols. In other words, specific deficits (be it speech or motor abilities), settings, and time limitations, prevented experts from being able to administer current measures. Instead, experts relied heavily on direct qualitative observations, rather than quantitative measures. The types of observations utilized combined what the expert visually witnessed with the patient's verbal self-report. One expert described their process as "asking them to do something, then asking them how they did, then seeing how accurate they are." One expert stressed the importance of noting discrepancies, "I look for differences in what they think they can do and what they actually do." Another expert valued observing the patient's ability to respond to their environment. They reported, "I watch them... if you can vary your response depending on what a situation demands, this shows self-awareness."

In terms of self-reports, one expert listens to the patient's understanding of their injury and their ability to self-reflect. The expert worked to answer the question, "Can they self-reflect on these things or just go about their day doing whatever is on their mind?" and used this observation as an inherent measure of their level of awareness. Another expert incorporated gathering the patient's self-reflection into their testing process. At various times during testing, they would ask their patient "How do you think that went?" or "How was that for you?" and noted differences between their performance and their self-report.

Assessment Techniques. All but one expert commented on the value of a strong clinical interview in their assessment of awareness. This allowed them to gather information surrounding pre-morbid functioning and important bio-psycho-social factors that may contribute to the patient's presentation. The assessment of awareness was likened to the process of assessing for capacity, one expert stated, "I treat it like a capacity evaluation...I listen to how they speak about their injury. What do they know, how much do they understand?" This expert assessed awareness based on the individual's ability to describe their mechanism of injury, the consequences of their injury, and the advantages and disadvantages of certain actions and behaviors. Inquiry into how the patient would perform a basic task (e.g., the process of starting a car) was also debated, as it allowed experts to assess the patient's knowledge of what a task may require and what challenges they may face in completing it. However, another expert aptly highlighted, "being able to say how you do something does not mean they can actually do it."

Executive functioning measures represented another category of assessment utilized. Experts believed that problem solving, abstract reasoning, and learning-to-learn, represented proxies of awareness. For example, one expert stated, "Problem solving measures and abstract reasoning measures can get at their ability to navigate their environment. These are tied to limitations in awareness." Three experts identified the Behavior Dyscontrol Scale (BDS). The Behavioral Dyscontrol Scale (BDS; Grigsby & Kaye, 1996) is a brief, nine-item neuropsychological measure that uses a variety of novel tasks to measure aspects of dynamic behavioral control and alphanumeric sequencing. In other words, the BDS measures a person's ability to activate, inhibit and control their motor functions. The test also has patients reflect on their performance upon test completion. Experts emphasized that the patient's reflection at the end of the test, illuminated the patient's awareness of their limitations in the assessment. The

primary limitation of the BDS was that it is normed on geriatric populations aged 65 and over, meaning no norms are available for younger individuals who had sustained an injury.

The BDS and Matrix Reasoning subtest of the Wechsler Adult Intelligence Scale-IV (WAIS-IV) was also mentioned as known indicators of abstract reasoning abilities. Abstract reasoning was thought to represent another proxy of awareness. Other tests, such as the Wisconsin Card Sort Category Test and Tactual Performance Test (TPT) were also noted as useful tests that provided helpful information in assessing awareness. For example, both tests require an individual to “adapt their response based on environmental feedback” (learning to learn), a necessary skill in awareness. However, experts acknowledged that these tests are “not data-driven awareness assessments, just proxies with interpretive limitations.”

Collateral Reports. Collateral reports arose in all interviews, though experts were divided over the extent to which they found these helpful. One expert stated, “I’m careful with collaterals because they may have their own biases, but someone who knows the patient’s pre-morbid functioning as compared to their current functioning is really helpful.” Collateral reports allowed one expert to assess, “[do] what the patient is saying and what others are saying match up?” Collateral reports can also be gathered from treatment team members and caregivers, whose reports were thought to be more reliable.

Treatment

Treating Awareness Deficits. Experts were unanimous in acknowledging the significant difficulty of treating awareness deficits. One expert noted, “I don’t know of any evidence-based therapeutic interventions for treating awareness deficits.” Another shared, “It doesn’t matter what I try to do with these folks. If they cannot acknowledge in that moment that they’re having a hard time, then they cannot apply this to their lives and change.” One expert cited a recent

study released by Villabos et.al. (2019), that utilized repetition of psychoeducation and the facilitation of memory compensation through teaching note taking skills as part of a Spain-based comprehensive day treatment program (8 sessions over the course of 4 weeks). Effectiveness of the intervention was based on increased scores in the Lawton Instrumental Activities of Daily Living Scale (Lawton IADL) to measure the functional changes in patients with respect to instrumental activities of daily living. Thus, increases in functional ability were used to determine the efficacy of awareness-based interventions. A significant difference in functional outcome improvements between an experimental and control group were found ($Z = -2.01$, $p = .04$, Cohen's $d = 0.56$). The experimental group exhibited higher functional outcome improvements than the control group in post-treatment assessment. The expert was quick to acknowledge the study's limited applicability, as the 56 participants represented a mixture of stroke, tumor, and other neurological diseases (e.g., dementia) instead of those with TBIs.

Psychoeducation. The most commonly mentioned intervention was the provision of psychoeducation to team members and caregivers. This overcame the challenge of patient buy-in, and also prioritized utilizing others to support patient safety. One expert noted, "I make sure the team and family are aware that the patient is, well, unaware of their injury. It's less about treating them and more about keeping them safe." Another expressed that when providing psychoeducation, she emphasizes "practicing self-compassion. Sharing with caregivers and medical providers that the patient cannot control this. It is great when you can help other providers to understand that this person is ill." Doing so limits the aforementioned impact of misattributing the patient's behaviors as volitional or purposeful.

Providers also reported simultaneous provision of psychoeducation to the patient. One expert does this in hopes that, “educating the patient creates buy-in.” Psychoeducation for the patient and all stakeholders in their care, allows for a shared understanding of their presentation.

Compensation. The second most common intervention category was teaching the patient compensation strategies. One expert stated, “You can make someone more aware, but you can teach someone to modify their behaviors.” For example, one expert has the patient develop, “...a series of questions you can ask yourself before you make a decision.” Another, expert shared that they, “Treat around the issue. Impulsivity, disinhibition and problem-solving training. The hope is slowing them down enough for them to utilize other parts of their brain to prevent injury.” In this way, experts provide compensation strategies as a means of minimizing the potential negative effects of an awareness deficit on everyday functioning.

Structured Failure. When talking about activities that encouraged structured failure, experts noted that these activities were often “time consuming with slow results.” What the current study has categorized as a structured failure task is one in which the patient is purposefully asked to complete an activity that is challenging for them. This task is facilitated by the psychologist in a safe environment and provides a shared example of a limitation that could be referred to and used as a measure of growth.

Potential Awareness Measures

While inquiring about possible new measures of awareness, experts were asked to assume that cultural factors such as age, severity of injury, educational level, and sex would already be accounted for. This restriction was made to focus expert recommendations on the measurement of awareness itself.

Rating Categories. All experts interviewed shared a strong desire for a quantifiable and shared rating system for awareness deficit severity. This would allow them to quickly differentiate between the severity of awareness deficits in various patients across settings and disciplines. One expert emphasized the importance of recognizing that awareness ranges across a spectrum. They reported, “I do not like the term borderline but in something like this, it is useful to have those ranges.” Another believed that having ratings would allow, “...for differentiation between levels of awareness and therefore, the ability to measure improvement.” This implied the need for a test with strong test-retest reliability, as awareness can rapidly change in the course of TBI recovery.

Pre and Post-Test Reflection. The importance of incorporating a pre and post-test reflection was considered essential. As one expert described, “The person needs to have the opportunity to demonstrate their ability or inability...then check in with them to see if they noticed that it has changed. It is more about their inability to recognize when something is not working.” Pre and post-test reflection would target the specific discrepancies that experts attempt to identify through clinical interviews, formal assessments, and collaterals.

All but one expert cited the importance of a performative element to the assessment. As part of this performative task, the patient would be asked to predict their performance based on their current abilities, asked to complete the task, then asked to reflect on how their actual performance compared to their predicted performance. Experts emphasized that this was important for observation of discrepancy between predicted and actual performance, and the ability to test if the patient understands “on an intellectual basis what they are doing behaviorally”. Thus, opportunities for self-reflection before and after the performative task were perceived as necessary components of awareness assessment.

Novelty. In terms of what the performative task entailed, experts were of two opinions. Six experts emphasized the need for a novel task, one stated, “A novel problem-solving task that allows them to reflect on what they think their abilities are as it relates to being able to complete this new task effectively.” A novel task that required the application of existing skills to something unfamiliar was believed to allow for greater reflection. Thus, it was believed to elicit a cleaner measure of self-awareness. Other experts felt that it would be too hard to control for spurious factors in a completely novel task. For example, an expert noted, “I would want the task to have the person reflect on something they could do before [the injury] and compare it to how they may do on it now. Do they recognize it will be harder now? That is the awareness piece to me.” Thus, experts were divided as to whether the application of old skills to a new task, or the repetition of an old skill in the context of their injuries, would yield the best measure of awareness.

Short, Valid, Reliable. Understandably, experts emphasized a strong desire for a short, valid, and reliable measure that could easily be administered. One expert highlighted, “Remember this may be someone who does not think they have a problem. Their buy-in is already limited.” Another shared, “The current measures we have require a lot of time to circle and respond to answers. That in and of itself requires buy-in. We need something relatively quick. Maybe 10-15 minutes?” Finally, an expert spoke to time limitations in their role as a consultant and liaison to an inpatient rehabilitation setting and shared that ideally, they would like something, “Data driven, not just opinion based. A quick measure that can be given bedside or even completed by the patient themselves.” A short, reliable, and valid measure not only overcomes the issue of buy-in, but also alleviates the time restrictions faced by several providers.

Conclusions

The information gathered in this study identifies a potential universal definition of self-awareness as well as performative tasks used to assess self-awareness, which when integrated could offer a quick and reliable way to determine one's level of self-awareness. This classification then would potentially provide a uniform way to understand the severity of one's self-awareness deficit post injury, and guide treatment.

Experts purport that current measures of awareness were either ineffective, time consuming, or had limited construct validity. As such, they are not using them. This implies that at this time, testing and measuring self-awareness is more ideographic than an evidence-based nomothetic endeavor. This is an important concern, given that self-awareness deficits have been found to be correlated with poorer treatment adherence and overall prognosis following TBI. The absence of a universally accepted definition of self-awareness and reliable measures of it, has seemingly forced experts to rely on their own clinical judgment, which is not the optimal situation. Individuals with self-awareness deficits may not be properly identified and are therefore, not receiving treatment for a factor that is highly correlated with positive TBI rehabilitation outcomes.

Fortunately, this study shows that the definitions of self-awareness being currently used by experts reveals a strong consensus. All experts identified the three key elements that a standardized definition should include a patient having a clear level of consciousness, accurate assessment of one's limitations, and insight into implications of the deficits. Interestingly, each identified factor relies on the presence of the factor that preceded it. This definition supports the experts' beliefs that awareness exists on a spectrum and that a meaningful assessment of awareness would allow for differentiation between varying levels of severity. In accordance with these beliefs, the following self-awareness rating table integrates these results into a simplified

system that could serve as the foundation for a universal definition and severity rating for moderate to severe traumatic brain injuries.

Table of Awareness Ratings.

P R E S E N C E	Orientation to Self	Orientation to Environment	Accurate Knowledge of Functional Limitations	Accurate Knowledge of Implications	Awareness Rating
	Present	Absent	Absent	Absent	Very Poor
	Present	Present	Absent	Absent	Poor
	Present	Present	Present	Absent	Moderate
	Present	Present	Present	Present	Intact

This table could serve as a screener that can be quickly administered by the treating psychologist in multiple settings. The screener would allow information to be communicated quickly and clearly between providers across disciplines. Assessing for the presence of each domain can be done verbally in person (assuming the patient is verbal with no expressive or receptive aphasia) or can be pulled from pre-existing information in the chart. For example, the Orientation Log (OLOG) (Novak, 2020) is commonly administered daily in rehabilitation settings to track emerging consciousness following a TBI. This measure provides information about orientation to self and environment. Further information to complete the rest of the screener can be gathered from the progress notes of other disciplines. This accounts for any time limitations faced by providers, particularly those in consult/liaison positions, and limits contact should a site need to adhere to current covid-19 precautions or other such limitations.

If experts remain unsure of the individual's level of awareness following a clinical interview and chart review, the administration of a performance-based task with a pre and post

reflection can be completed. Regardless of differing opinions surrounding patient familiarity with a task, experts agree that the purpose of the task is to see if the individual can reflect and accurately identify the implications their deficits may have upon task completion. The opportunity for pre-reflection would provide information about the accuracy of an individual's knowledge of their limitations. The post-reflection then allows the psychologist to assess if the individual is capable of accurately acknowledging the functional implications of their deficits. Finally, the performative task has the added benefit of serving as an awareness intervention in and of itself.

One option for this performative task would be the Tactual Performance Test (Boll, 1980) or an adaptation of it. Three experts posited that this was the best representation of the performative task they had in mind. In this task, blindfolded test takers are asked to place cut out wooden shapes into their respective holes. It seems the same task can be recycled with the addition of more barriers to offer greater opportunities for the identification of challenges. For example, an additional parameter of restricted time can be added for those with higher cognitive functioning amidst a self-awareness deficit. However, the TPT is intended to measure motor abilities and recall of motor stimuli. This limits its utility for those with severe motor deficits who cannot complete the task, and those with no motor deficits for whom the task may be too easy. Further information surrounding the specific aspects of the task that experts are drawn to would have been helpful information but was not collected as part of this study.

Both the rating system and performative measure would further need to be researched and normed on a brain injury population. The rating and performative measure would also need to account for normative brain injury recovery timelines and be tested across multiple settings to ensure proper validity and reliability.

Limitations of This Study

The Qualitative data collected would benefit from being replicated and analyzed quantitatively to ensure reliability and validity. The scope of the questions explore may also not cover all relevant aspects **of current practice**. As the information provided was based solely on the self-report of nine experts in one area of the country and may not represent the full spectrum of professional opinions. The experts interviewed were limited to those serving in the Colorado area with some form of connection to this researcher. The findings of this study may also represent regional influences on the treatment and assessment of awareness. The scripted questions utilized may have limited the information shared or prevented the emergence of other critical aspects. While all experts interviewed have worked with brain injuries for at least 10 years and are board certified in rehabilitation psychology, further demographics were not collected, nor was information regarding number of awareness deficit cases treated.

Future Research

To augment the paucity of literature surrounding how to best define, assess, and intervene with awareness deficits in those with moderate-to-severe TBIs, this study interviewed nine experts currently practicing in the field of TBI rehabilitation psychology in Colorado, USA. This paper highlighted a potential universal definition of TBI that was developed by integrating the shared consensus among these experts. The belief that awareness likely existed on a spectrum was confirmed by experts and an awareness rating table was proposed. Further research into the specific application of these findings is warranted. For example, surveying a larger sample of experts and quantitative application of the rating table to test validity and reliability.

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APPENDIX

Appendix 1: *Definitions of Awareness Categories*

Definition of Awareness	
Categories	Subcategories
Consciousness:	<p>Of the injury</p> <p>“An understanding of the impact of the injury, what happened, and what it means”</p> <p>“A person who is still emerging from a coma or who is in post-traumatic amnesia (PTA) does not have awareness.”</p> <p>“During PTA a person may be oriented to who they are but lack awareness of what has occurred to them”</p> <p>“Awareness requires someone to be aroused or awake enough to know where they are and why they are there”</p>
Accurate knowledge of current functioning/abilities	<p>“Person’s personal awareness of their own functional level and whether or not that functional level matches with their abilities and their execution of their abilities”</p> <p>“conscious awareness of how one is functioning in a particular context.”</p> <p>“An individual’s ability to accurately assess their own abilities, their own way of being in the world, and their functioning.”</p> <p>“Ability to accurately describe strengths and weaknesses”</p> <p>“...an inability to acknowledge limitations when it reduces their abilities to set goals and engage in treatment. With the right cognitive capacity a person can have awareness of a deficit but they may not agree with it. They don’t have insight but they’re aware that this bothers their family.”</p>
Insight	<p>As a measure of awareness</p> <p>“Lack of awareness suggests poor insight and poor judgment”</p> <p>“Awareness requires consciousness but not necessarily insight”</p> <p>“Insight into their own deficits or how others perceive them and whether or not those deficits will impact their personal lives, schools, community and family.”</p> <p>Separate from awareness:</p>

	<p>“Insight feels more retrospective than awareness which feels more present. Insight is an accumulation of awareness-invoking experiences”</p> <p>“Insight gets built based on a collection of evidence. Insight is somebody being aware based on past experience that this is something they can’t do. Accumulation of information over time. Awareness is in the moment.”</p>
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appendix 2: *Impact on treatment categories*

Impact of Awareness on Treatment	
Categories	Subcategories/Supportive Quotes
Treatment Engagement	<p>Reduced Engagement</p> <p>“A lack of awareness is often correlated with a lack of motivation and a lack of desire to be in treatment.”</p> <p>“A lack of awareness could influence treatment planning from a team perspective.”</p> <p>“If the patient doesn’t think there’s something wrong. Why would they work with their team and family to fix it?”</p> <p>“The lack of buy in from a patient is highly detrimental to treatment engagement.”</p>
Prognostic Factor	<p>“...Prognostic indicator. In order to heal and recover from injury one has to appreciate one’s own role in doing that. The team is there to help foster recovery but you need to recognize your role as a patient and why you’re here. If you cannot see your own role within the recovery process, you cannot see how your behavior and engagement may effect that outcome.”</p> <p>“A lack of awareness means they will not do the things necessary to recover. This, understandably, hurts their rehabilitation and long term recovery.”</p> <p>“Team members can be wary of working with a patient who constantly pushes back on</p>

	treatment or denies the need for it. This hurts the patient long term.”
Misattribution	<p>By the team “The team can misattribute a lack of progress to something volitional.”</p> <p>“Team members often become frustrated with these patients because they experience the patient as resistant or challenging. Even if they know otherwise, it’s emotionally taxing to navigate.”</p> <p>By the family “Support systems are key in TBI rehabilitation. Family conflict often arises when family members think the patient is in “denial” or refusing treatment willfully.”</p> <p>“Caregivers can become extremely frustrated with their loved one. The patient may feel like they can drive or be unwilling to follow procedures.”</p> <p>“It hurts their support system. People do not want to work with them because it’s frustrating for the family and the team.”</p>
Increase safety risks	<p>“poor judgment, persist in behaviors that don’t work for them and that may be harmful”</p> <p>“Increases their risk of a secondary injury.”</p> <p>“If a patient does not believe they need to follow safety procedures, they risk further injuring themselves and their providers”</p> <p>“Poor awareness leads to poor judgment, causing them to persist in behaviors that don’t work for them or that worse, hurt them.”</p>

appendix 3. *Assessment of Awareness Categories*

Assessing Awareness	
Categories	Subcategories/Supportive Quotes
Observation	Visually Witnessed

	<p>“Accumulation of evidence based on observations of them. E.g. asking them to do something, then ask them how they did, then seeing how accurate they are.”</p> <p>“I look for differences in what they think they can do and what they actually do.”</p> <p>“I watch them... if you can vary your response depending on what a situation demands shows self-awareness.”</p> <p>Patient Self-Report “Hearing someone’s internal dialogue, and them articulating how things have been going in testing with what is actually happening.”</p> <p>“I listen to how a person describes their injury and their care. Can they appreciate how their behavioral disturbances may be influencing their relationship with their spouse or kids. Can they self-reflect on these things or just go about their day doing whatever is on their mind.”</p> <p>“Disconnects between self-report and testing”</p>
<p>Assessments</p>	<p>Clinical Interview “A semi-structured interview that I use when I do my evaluation. I ask: Tell me why you’re here; Tell me what happened; Tell me about your cognitive problems.”</p> <p>“I sometimes use a FrSbe or another measure where I ask them and their families the same questions and look for discrepancies in reporting.”</p> <p>“I’ll ask them if they think they can do something, like drive, then ask them to walk me through how to start a car and drive is safely.”</p> <p>“I just listen to how they speak about their injury. What do they know, how much do they understand it. Almost like a capacity evaluation.”</p> <p>Executive Functioning Measures “Executive functioning measures like the BDS (Behavior Dyscontrol Scale) that requires them to reflect on how they did”</p>

	<p>“Having a built-reflection (like on the BDS) allows me to see if they can understand their limitations and abilities.”</p> <p>“Often problem solving measures and abstract reasoning measures can get at their ability to navigate their environment and show limitations in awareness.”</p> <p>“Verbal and non-verbal abstract reasoning ability so getting someone to do Matrix Reasoning or the WCST. Having cognitive flexibility allows for introspection and therefore shows awareness. The novel task also means they can’t really know how they’ve done.””</p> <p>“Wisconsin Card Sort? Category Test, Tactual Performance Test (TPT), tests of problem solving, inhibition, planning, BDS. MacArthur assessment of capacity.”</p>
Collateral Reports	<p>“These can be from the team or family. Is what the patient is saying and what others are saying match up?”</p> <p>“I’m careful with collaterals because they may have their own biases but someone who knows the patients pre-morbid functioning as compared to their current functioning is really helpful.”</p>

appendix 4. *Treating Awareness Deficits*

Treating Awareness Deficits	
Categories	Subcategories/Supportive Quotes
Difficult and Challenging	<p>“It is very very challenging. I am not aware of any evidence based therapies.”</p> <p>“It doesn’t matter what I try to do with these folks. It doesn’t matter if they cannot acknowledge in that moment that they’re having a hard time then they cannot apply this to their lives and change.”</p>

	<p>“It helps to recognize our own limitations with this, especially if the etiology is organic (right frontal injury) but even when it’s not. It’s so challenging to treat.”</p> <p>“I try to teach them but this honestly does not work too well.”</p>
<p>Psychoeducation</p>	<p>For Family and Team</p> <p>“I make sure the team and family is aware that the patient is, well, unaware of their injury. It’s less about treating them and more about keeping them safe.”</p> <p>“It’s important to educate caregivers and working with them to identify potentially dangerous situations for their loved one. Teaching, coaching and problem solving with the caregiver.”</p> <p>“Working with families to address the lack of awareness and support them with it. I encourage them to have grace and compassion for themselves and the patient.”</p> <p>“Practicing self-compassion. Sharing with caregivers/medical providers that the pt cannot control this. It’s great when you can help other providers to understand that this person is ill.”</p> <p>For Patient</p> <p>“I try to help them gain awareness through repetition. In a structured way, I remind them and have those around them remind them of their injury and its implications.”</p> <p>“Education. I hope that educating the patient creates buy in.”</p> <p>“Repetition in terms of errorless learning can compensate but doesn’t improve awareness.”</p>
<p>Compensation Tools</p>	<p>“Let’s write out a series of questions you can ask yourself before you make a decision.”</p> <p>“I say “this part of your brain is not working so having a trusting person to run things by even if</p>

	<p>you don't think you need to, allows them to use that part of your brain for you.”</p> <p>“Give them a task that they think they should be able to do. Have them talk about that task. With repetition you can see movement there but it's hard.”</p> <p>“Treat around the issue. Impulsivity, disinhibition and problem solving training. The hope is slowing them down enough for them to utilize other parts of their brain or prevent injury.”</p> <p>“You can't make someone more aware but you can teach someone to modify their behaviors. People often think that if we can provide them with more knowledge then they'll be more introspective but it isn't that simple. It's like training someone to be more moral or ethical in their decision making which is different to being aware that their behaviors have consequences.”</p>
<p>Structured Failure</p>	<p>“The helpful way is to allow them to fail. Creating a space where they could fail safely. Then say, “what's wrong?”</p> <p>“Give them a task that they think they should be able to do. Have them talk about that task. With repetition you can see movement there but it's hard.”</p> <p>“It's the opposite of errorless learning, forcing them to make a mistake to get them to recognize that they have limitations.”</p>

appendix 5. *New Awareness Measure Inclusions*

<p>New Awareness Measure Inclusions</p>	
<p>Categories</p>	<p>Subcategories/Supportive Quotes</p>
<p>Rating Categories</p>	<p>“Rating scales of some sort. “More likely, less likely or just as likely to help you.””</p>

	<p>“A quick measure that can be done that can show “likely vs. very unlikely vs. highly likely”</p> <p>“It’s important to speak about these things in ranges because everything occurs on a spectrum. I don’t like the term borderline but in something like this, it’s useful to understand the level of impairment.”</p> <p>“I’d want a rating of some sort that would allow for differentiation between levels of awareness and therefore, the ability to measure improvement.”</p>
<p>Pre and Post Self-Reflection of a Performative Task</p>	<p>“The person needs to have the opportunity to demonstrate their ability or inability be it historical or presently, then check in with them to see if they noticed. It’s more about their inability to recognize when something isn’t working.”</p> <p>“Asking them how they’d do on something and then testing that. Do they then adapt to it? Can they understand why they failed?”</p> <p>“Is there self-report consistent with their testing or reporting problems they don’t have. Ability to show awareness of why someone else might struggle and then applying it to themselves during a task of some sort.”</p> <p>“A performance piece and an evaluation piece... I am going to have you do...how do you think you’ll do? Have them do it. How did your actual performance compare to your predicted performance?”</p> <p>“Have them do a novel task of some sort. Before, during and after the test “Tell me right now how you think you’re performing so far”</p> <p>“If someone tells me that they recognize that because of their injury they cannot drive, then I see them getting into their car then there is a difference between what they understand on an intellectual basis and what they are doing behaviorally. We have to test both.”</p>

<p>Novelty</p>	<p>Task should be novel and challenging “Best accomplished through novel situations where they are required to apply their perceived abilities to something new.”</p> <p>“A novel problem solving task that allows them to reflect on what they think their abilities are as it related to being able to complete this new task effectively.”</p> <p>“Something new that they can fail at.”</p> <p>“Short and can administer on the fly. Something that is not too overlearned. Something like Matrix Reasoning where you don’t know if you’ve gotten it right or wrong. You can think you know but it’s not necessarily obvious.”</p> <p>“A sorting task of some sort maybe. Something new that builds on old skills but is also not culturally biased.”</p> <p>Task should be known “If you’re going to measure awareness, it would need to be something they’ve done before. For example, pay a bill or take your medicine. A familiar task that would be impactful to their lives in some way. Do you think you can do that? Go do it. How did it go?”</p> <p>“I’d want the task to have the person reflect on something they could do before as to how they may do on it now. Do they recognize it’ll be harder now?”</p> <p>“Give them a task they know how to do. Ask them why it might be harder or easier now.”</p>

Short and valid/reliable	<p>“The current measures we have require a lot of time to circle and respond to answers. That in and of itself requires buy in. We need something relatively quick. Maybe 10-15 mins?”</p> <p>“I’d want it to focus just on awareness. A short simple measure that can be given at discharge.”</p> <p>“We have several executive functioning measures that are considered proxies of awareness. I’d want one that directly measured it.”</p> <p>“It needs to be data driven, not just opinion based. A quick measure that can be given bedside or even completed by the patient themselves.”</p>
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