DSHS CARE TOOL MENTAL HEALTH ASSESSMENT ANALYSIS: IS IT ADEQUATE IN WASHINGTON STATE?

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ABSTRACT: The Comprehensive Assessment Reporting and Evaluation (CARE) Tool is a large-scale holistic assessment that is currently being used by Washington State's Department of Social and Health Services (DSHS). The CARE tool serves as a way to determine the care eligibility for people who may need to become involved in long term community services such as skilled nursing facilities or rehabilitation facilities. However, some people have difficulty with being able to access these long-term community services even though they need help with their Activities of Daily Living (i.e. eating, bathing, getting dressed, and mobility). To be more specific, people who have acquired traumatic brain injuries is an example of a patient population who have experienced hardship with being able to access long term community services, despite the CARE tool being in place.

That being said, it was found that the CARE Tool is not as sensitive to the psychological signs and symptoms that are present when someone is first diagnosed with traumatic brain injury in the hospital setting. The CARE Tool only assesses patients in the hospitals based on the day of the assessment and seven days prior to the assessment date. In other words, it is not designed to predict potential significant changes or needs that a patient may end up desperately needing in the next 1 to 2 years.

Based on this issue of assessment tool sensitivity, a literature review was conducted and it was found that there are multiple other behavioral and mental health assessment tools that can be used in lieu of the current behavioral and MMSE that are more sensitive to milder psychological signs and symptoms. In conclusion, it was found that the CARE Tool behavioral and MMSE assessments that are found within the CARE Tool needs to be changed by enacting policy change.

Problem Statement

The Comprehensive Assessment Reporting and Evaluation (CARE) Tool is a large-scale holistic assessment that is currently being used by Washington State's Department of Social and Health Services (DSHS). The CARE tool serves as a way to determine the care eligibility for people who may need to become involved in long term community services (Northwest Justice Project, 2018). Long term community services include health care that may be needed for 6 months or longer such as skilled nursing facilities, assisted living facilities, or rehabilitation facilities. Sometimes, an individual may need to access these long-term community services for the rest of their life which can be costly. This is especially true if an individual needs to access these community services on a daily basis. That being said, a certain number of hours is determined as a maximum amount of hours that the state will pay for an individual. This certain amount is based on a person's results from the CARE tool, which may or may not be accurate.

Washington State Legislation gives the notion that the CARE tool may not be accurate because of the ability to apply for an Exception to Rule process (Northwest Justice Project, 2018). The Exception to Rule process gives the opportunity for individuals to ask Washington State Legislation for more hours

allotted per month for individual one-on-one care if an individual feels that they need more help than the state originally thought they needed. For example, some individuals may only be eligible for fifty to one hundred hours per month of one-on-one care upon initial assessment with the CARE tool. However, the individual may later find that they need more hours of one-on-one care down the road, when medical and psychological conditions get worse. Worsening medical and psychological conditions would be evident when the individual cannot perform their Activities of Daily Living (ADLs) anymore such as independently dressing or eating.

The Exception to Rule process also brings to light that care related to mental health as a consequence of a chronic injury may not be reflected in the CARE assessment tool. The CARE tool only assesses what has happened with an individual over the last seven days from the day of the assessment (Northwest Justice Project, 2018; Washington State Department of Social & Health Services, 2003). That being said, the CARE tool is not able to analyze worsening medical and psychological conditions over time. The CARE tool is only able to provide higher numbers of one-on-one care hours if the medical and/or psychological conditions are presented as worsening over the course of the last seven days from the day of the CARE tool assessment. This may not be realistic depending on what medical and/or psychological conditions the individual may have. This is where the logistics behind how the number of care hours are determined for each individual can get confusing because a lot of psychological or mental health issues can be presented as very subtle when first diagnosed.

When looking at the logistics behind how the number of care hours are determined for each individual, mental health status and behaviors are rated lower than those who are considered clinically complex. Washington State Legislation determines that those who are clinically complex and who also have a higher score on the cognitive and behavioral scales are given about one hundred more hours per month, as compared to those who may not be clinically complex and still have cognitive and/or behavior issues that greatly affects their ability to complete Activities of Daily Living (ADLs) (Washington State Legislature, 2005a; Washington State Legislature, 2005b; Washington State Department of Social & Health Services, 2017). For example, someone who may need hemodialysis and has mild dementia that does not currently affect their ADL completion (and will not for multiple years) automatically gets more one-on-one care hours as compared to someone who is relatively healthy but has a moderate-level traumatic brain injury that the individual has been told will get significantly worse as time goes on. In other words, the individual with only the moderate-level traumatic brain injury is known to have a worsening psychological condition that will eventually affect their ADL completion, but the CARE tool cannot assess for this expected worsening psychological condition because it is not designed to continuously assess the individual. It is basically designed as an initial assessment to get individuals introduced to the long term care system in Washington State.

Taking all of this into account, it is best to analyze an example of a population of patients that continues to struggle to get adequate one-on-one care hours approved by Washington State Legislation. A population of patients who may be greatly affected by not getting enough hours for individualized care are those who have acquired traumatic brain injuries (TBI). TBIs are complex medical issues that can affect everything about an individual from ADL completion ability to the quality of cognitive and behavioral health. A more formal definition of TBI involves damage to the brain that occurs after birth as a result of an external force (Dams-O'Connor, Landau, Hoffman, & St De Lore, 2018). However, TBIs are not listed in the clinically complex list of medical issues found within the CARE tool, even though the conditions that are listed in the clinically complex list are diseases that often require frequent hospitalizations over time. That being said, multiple studies have found that TBI falls under the World Health Organization's definition of chronic health conditions because of the functional decline that can occur over time (Dams-O'Connor et al.,

2018; Harrison, Hunter, Thomas, Bordy, Stokes, & Kitzman, 2017). Concerning symptoms that individuals living with TBIs may have include balance issues, extremity weakness, memory issues, hallucinations, changes in the sensory systems of the body, dizziness, and vision changes. All of these can cause an inability to complete ADLs over time even if it is not seen immediately after acute care discharge (Dams-O'Connor et al., 2018; Harrison et al., 2017). A common issue that these patients have is that they see these concerning symptoms over time, yet the number of hours that have been approved by the state's government system is usually not consistent with the progression of the condition that individual sees (Harrison et al., 2017). In other words, the individual is not being approved for a higher number of care hours when they notice that their symptoms are worsening.

That being said, the CARE tool is by all means comprehensive overall. Still, adult TBI patients may not be adequately assessed for behavioral and cognitive care needs through the current use of the CARE tool because both assessments that make up the behavioral and cognitive (Mini-Mental State Examination) components of the CARE tool requires more information than what the current CARE behavioral and Mini-Mental State Examination (MMSE) assessments can provide.

Literature Review

Although no studies currently exist that examine the CARE tool specifically, a small group of studies were found regarding the use of different types of behavior and cognition assessments that could be incorporated into the CARE tool. That being said, it is important to mention that this literature review had the aim of figuring out what other behavior and cognitive assessments currently exist and are in current use. This literature review was conducted through a CINAHL Complete database search. Search terms included "behavioral assessment," "cognitive assessment," and "Traumatic Brain Injury." All studies included were limited to a 2015-2020 publication date and were peer-reviewed. A review of the literature revealed a mixture of

qualitative and quantitative studies. This included: nonrandomized two group comparisons (Kelly, Simpson, Brown, Kremer, & Gillett, 2019; Schwartz, Averbuch, Katz, & Sagiv, 2016), a longitudinal crossover study (Zhang et al., 2016), an observational cross-sectional study (Tran et al., 2018), a secondary analysis study (Zarshenas & Cullen, 2018), and a focus group qualitative assessment development study (Juengst, Terhorst, Dicianno, Niemeier, & Wagner, 2019).

Looking at one of the two nonrandomized two group comparison studies first, Kelly et al. (2019) conducted a study consisting of a mixed brain injury (MBI) group and a primary brain tumor (PBT) group with the majority of MBI participants being diagnosed with TBI. The MBI group consisted of 34 participants from two healthcare agencies in Australia. The main study outcome measures included Observational Behavior Scale-Adult (OBS-Adult) scores and Observational Behavior Scale- Self Report (OBS-SR) scores to see if self-reporting of potentially challenging behaviors would produce similar scores of the OBS-Adult assessment for behavior and cognition. Kelly et al. (2019) found that the MBI group had a statistically significant result when it came to differences in scores between the participant and trained observational assessor in scores for cognition and challenging behaviors, where variations in scores increased. This is important because the MBI group thought that their presenting symptoms were different than how the assessors were scoring their symptoms, whereas the PBT group showed no significant difference in scores. Limitations to this study included having different trained observational assessors for each group and not considering the severity of each brain injury (Kelly et al., 2019).

In the second of the two nonrandomized two group comparison studies, Schwartz et al. (2016) conducted a study consisting of 25 participants in the TBI group from inpatient and outpatient units at the Lowenstein Rehabilitation Hospital, and 25 participants in the healthy control group (no TBI diagnosis). Both groups had 19 men and 6 women and were between 18-50 years old. The main

study measures were the Functional Lowenstein Occupational Therapy Cognitive Assessment (FLOTCA) and a combination Functional Independence Measure (FIM) and Functional Assessment Measure (FAM) to see if there were any correlations between baseline demographic data and the scores for each measure. Schwartz et al. (2016) found that there was a negative correlation between average number of days unconscious in the hospital and total FLOTCA scores and a positive correlation between Glasgow Coma Scale (GCS) scores and total FLOTCA scores, with an over 95% confidence interval for both findings in the TBI group. The discovery of the positive and negative correlation in the TBI group is especially important because those who have been diagnosed with TBI can have a range of cognition scores and still have the diagnosis of TBI, which can affect ADL completion. The limitations to this study were that this was not a randomized control research design and the sample size was small in both groups, with unequal gender representation (Schwartz et al., 2016).

The next study involves a longitudinal crossover research study by Zhang et al. (2016). Zhang et al. (2016) conducted a study consisting of a TBI group of 103 participants and a stroke group of 127 participants, all who were selected by diagnosis from the China Rehabilitation Research Center based on American diagnostic criteria. The average age of participants was 35 in the TBI group, and the overall study had a majority of male participants. The measures of the study included MMSE scores and Montreal Cognitive Assessment (MoCA) scores to see if participants would have a normal score on one assessment and an abnormal score on the other assessment. Zhang et al. (2016) found that 87% of TBI group participants had normal MMSE scores but an abnormal MoCA score indicating that the MoCA assessment may be more sensitive than the MMSE. This finding has a huge impact on the current use of the cognitive component of the CARE tool because this study shows that the MMSE assessment that is found in the CARE tool is less sensitive to TBI symptoms as compared to the MoCA assessment. Limitations to this study

included the exclusion of severely cognitive impaired TBI patients (Zhang et al., 2016).

Taking into account the previous studies above, another study that is observational cross-sectional in nature was identified for analysis. Tran et al. (2018) conducted a study consisting of 36 TBI participants who were diagnosed with severe TBI and recruited from 3 brain injury rehabilitation units in Sydney, Australia. The average age of participants was 36 years old with an average GCS score of 6.5 (Tran et al., 2018). The measures of the study included Functional Assessment of Verbal Reasoning and Executive Strategies (FAVRES) assessment scores and the Sydney Psychosocial Reintegration Scale Version 2 (SPRS-2) questionnaire scores to assess if there was a correlation between lower FAVRES scores and lower psychosocial scores on the SPRS-2. Tran et al. (2018) found that 72% of participants had difficulty completing the FAVRES assessment at 12 months post injury and 100% of participants had some degree of psychosocial change as compared to pre-injury status which was shown by the SPRS-2 questionnaire. This is important to consider when assessing TBI symptoms because this study shows that TBI symptoms do get worse with time and that there needs to be ongoing cognitive and behavioral assessment of the patients who have been diagnosed with TBI. The fact that over half of the participants in this study had difficulty in completing a FAVRES assessment indicates that their ability to complete ADLs may be affected overtime because the FAVRES assessment includes ADL completion components. The study indicates that limitations include having a smaller sample size and not assessing levels of aphasia or language impairments (Tran et al., 2018).

Next, a secondary analysis by Zarshenas and Cullen (2018) was identified for review. Zarshenas and Cullen (2018) conducted a study consisting of 65 participants who were 18 years old or older and diagnosed with TBI who had been admitted to the Toronto Rehabilitation Institute between 2008 and 2011. The measures of the study included cognitive ability scores via the Cogstate Brief Battery (CBB) assessment tool mixed with the cognitive and motor

components of the FIM. These measures were used to see if cognitive and motor functioning varied in scores depending on if the CBB components were used or not. Zarshenas and Cullen (2018) found that the introduction of the CBB increased the variation of scores for cognition by about 48%. The addition of the CBB component, which is a cognitive assessment, increased the variation of the overall cognitive and motor components of the FIM scores because the CBB was able to pick up on subtle variations of cognitive ability scores for individuals with TBI. This additionally takes into account the fact that having an improved cognition improves the ability to complete motor components on the FIM assessment which can be linked to ADL completion. Zarshenas and Cullen (2018) indicated that their limitations in their study was having a small sample size and no data on comorbidities of participants.

Lastly, a focus group qualitative assessment development study was identified for review by Juengst et al. (2019). Juengst et al. (2019) conducted a study consisting of an expert panel of 6 TBI trained health professionals and two focus groups. The TBI participants were between 50-60 years old and 100% male in the first group with the second group being between 25-68 years old and 40% male (Juengst et al. 2019). The measurements of the study included expert panel scoring for clarity and relevance of assessment questions, content validity index, and focus group feedback on clarity of assessment questions (Juengst et al., 2019). Juengst et al. (2019) found that the Behavioral Assessment Screening Tool (BAST) assessment may decrease observer bias because it asks questions about participant behaviors at a level that is clear to them. This is an important finding because observer bias can impact how a person is scored on behavioral and cognitive assessments. For example, an individual with TBI may not be able to fully understand the questions that are asked on behavioral or cognitive assessments. This is important when considering the CARE tool assessment because this study demonstrates that lack of consideration for observer bias can greatly affect cognitive assessment scores. This shows that observer bias should be taken into

further consideration within the CARE tool, since the numbers written in the CARE tool assessment becomes the guideline for allocating the number of individualized care hours a person will be getting each month. In other words, the individual being assessed does not get to see the numbers listed on the CARE tool until the application has been officially processed by the state. Juengst et al. (2019) mentioned that there were several limitations to their study which includes the consideration of participant self-awareness of behaviors, only looking at a two week time frame, small sample size, and lack of test items sensitive to exaggerated claims by participants.

In consideration to the above-mentioned studies, it has been made clear that other assessments focusing on behavior and cognition exist. A lot of these assessments are currently in use and have successfully identified behavior and cognitive impairments that TBI patients may encounter in their recovery process. However, the majority of research studies found were qualitative in nature and no randomized controlled studies were found. All studies were limited in terms of having small sample sizes and bias could be present with the assessments involving self-reporting. There is still a major gap in research on reliable behavior and cognition assessments because there seems to be an interest in self-reported scores of TBI participants where bias and lack of self-awareness is an issue.

Argument

As was mentioned in the problem statement, the current CARE behavioral and cognitive assessments may require more information than what is currently found on the CARE assessment forms. In particular, behavioral assessments that involve patient self-reporting along with an external observer report of TBI patient behaviors could be incorporated to better describe the TBI patient's overall mental health status, rather than relying solely on subjective observations of behavior. Mental health assessments involve external and internal information from each individual patient who is seeking care. However, some patients with

poor mental health might be viewed by health care professionals as not being able to adequately provide valid information. Therefore, patients may need someone or something to help validate their mental health status whether it be another health professional, family member, or a medical record. That being said, the opinion representation of the validation material should not be valued higher in assessments as compared to direct patient verbalizations of experiences.

Mental health has to take into account the internal information of an individual which can only be described by the individual, much like how descriptions of pain are measured via individual verbalizations. Therefore, self-reporting mental health habits such as engaging in certain behaviors should be documented and assessed with equal value to the opinion of an external observer. There are a few assessment tools that are currently in use which assess self-reports of TBI patient's behavior alongside an external observer assessment of the same TBI patient's behavior. For example, Kelly et al. (2019) utilized the OBS as a behavior assessment tool to assess and monitor for challenging behaviors, and they came to the conclusion that patients living with TBI may be more aware of challenging behaviors if they are given examples of the behavior during the self-reporting portion of the assessment. This indicates that TBI patients may not be completely aware of descriptions of the challenging behaviors that the CARE tool screens for, especially if the behaviors that are assessed in the CARE tool are not explicitly defined for the patient during the CARE assessment. Kelly et al. (2019) also reported statistically significant results in regards to differences in the scoring of self-report and external observation for cognition and challenging behaviors. This indicates that self-reporting should not be the only thing that is relied upon for assessing challenging behaviors.

The most difficult part of a self-reporting assessment is getting reliable and valid results, which can lead other healthcare professionals away from not wanting to include self-reporting in behavioral assessments. However, Juengst et al. (2019) has been working on a new screening tool called BAST. This tool is which designed to decrease external observation bias by the way questions are worded about certain challenging behaviors. This tool also includes a more comprehensive assessment of support systems and potential stressors that could be triggering challenging behaviors. Incorporating tools like BAST could help long term care programs become more educated on items that could trigger certain behaviors. This could allow these care programs to perhaps become more accepting of these patients with challenging behaviors, once triggers have been identified.

In addition to the discussion of mental health, cognitive assessments for people who live with TBI is an essential assessment for this population because it can help with accurately getting their care needs met so that successful rehabilitation can occur. Specifically, cognitive rehabilitation should be a major focus for this patient population because care needs for TBI patients typically involve ways to cope with cognitive decline over time (Juengst et al., 2019; Kelly et al., 2019; Schwartz et al., 2016; Tran et al., 2018; Zarshenas & Cullen, 2018; Zhang et al., 2016). For example patients living with TBI may not have immediate memory or communication deficits, but may have difficulty in higher cognitive activities such as applying a list of instructions to a physical activity. There are assessments that exist to assess higher cognitive activities and detect more subtle changes in cognition. Zarshenas and Cullen (2018) have developed an integration of the CBB into an already utilized functional assessment tool to involve a deeper cognition assessment for disability measures. With the integration of the CBB components, it was found that TBI patients had difficulty in identifying common objects and in the completion of short-term learning tasks, which correlated with lower cognitive scores (Zarshenas & Cullen, 2018). Schwartz et al. (2016) developed the FLOTCA assessment tool to measure higher cognition based on sequencing logical steps in unfamiliar environments and found that GCS scores and FLOTCA scores correlated with each other. Tran et al. (2018) developed the FAVRES assessment to assess cognition with communication

skills. This tool asked participants to describe their rationales behind the steps that they take to complete a task and found that the participants had difficulty in completing the FAVRES about one year post injury as compared to immediately after acute care discharge.

All of these assessments show that some aspect of decision making can be difficult for TBI patients. These deficits can only be found if higher cognition assessments are completed.   Time is of the essence, and it has been noted that healthcare professionals who complete comprehensive assessments such as the CARE tool for patients may not want to add another assessment into the fifty plus page assessment forms. However, it should be duly noted that all assessments mentioned previously are designed to take less than 5 minutes (Juengst et a., 2019; Kelly et al., 2019; Schwartz et al., 2016; Tran et al., 2018; Zarshenas & Cullen, 2018; Zhang et al., 2016).

As mentioned previously, the CARE tool currently utilizes the MMSE for assessment of cognition. However, the MMSE may not be sensitive enough to capture more subtle deficits such as those that may be found in higher cognition activities. The MoCA assessment tool has been found to be more sensitive to identifying deficits of higher cognition in comparison to the MMSE. Zhang et al. (2016) found that 87% of TBI participants had normal MMSE scores but abnormal MoCA scores when the same assessor completed the two assessments together on a single participant. This indicates that the MMSE may not be as comprehensive as one may think, because the MoCA involves scoring items that have a unique focus on higher cognition items.

Discussion

The CARE assessment tool is comprehensive in its entirety when looked at as a whole, and this paper was not in any way claiming that the CARE tool should be thrown out completely. However, there is clear evidence from Washington State Legislation that states the number of care hours allotted per month for those living with mental

health issues are being distributed unevenly as compared to those who have physical and mental health conditions together (Washington State Legislature, 2005b). Furthermore, the findings from the various studies that were mentioned in the literature review section have all shown that there are other existing assessments that better assess various severities found in mental health issues. For example, the studies that were presented in the previous literature review section looked at mental health assessments that were able to pick up on more subtle symptoms, giving the participants a higher score on these assessments. This indicates a higher need of additional help for these individuals that scored higher. This also means that individuals who may have subtle symptoms of a mental health condition upon initial CARE tool assessment can potentially score higher for the number of one-on-one care hours, if any of these cognitive or behavioral assessments were to be added into the CARE tool. In other words, the addition of a more sensitive cognitive or behavioral assessment in the CARE tool would help adjust the scoring to be fairer towards those who present mental health issues that can worsen as time goes on.

Still, it should also be noted that there were common limitations with each of the studies that were presented in the literature review section. These included: some sort of discordance between how the participants viewed their symptoms and how the observers scoring the participants viewed the participants' symptoms, some studies only assessing very mild and very severe TBI symptoms or not considering severity of TBI symptoms at all, small sample sizes, and only observing a specific mental health condition which makes the studies non-generalizable to other mental health issues that are not related to TBI.

That being said, the issue now revolves around the politics behind the CARE tool. Just because there has been an identified need for a change to the CARE tool, does not automatically make the CARE tool able to be changed right away. There is an extensive process to this involving state governed politics at the Legislative level. Individuals can

submit a petition form to the DSHS to recommend changes to the CARE tool through the Washington State Legislation website (Washington State Legislature, n.d.). This can make the issue known to DSHS directly, although this action alone may not be enough. Washington State Legislators can also influence state agencies such as the DSHS to look into topics of concern and have the ability to change the wording of the laws related to Washington State health policies. So, the best thing to do would be to make this issue known to local state legislators who can notify both private and public groups to legally support a change in current health policies. An ideal response from State Legislation would be the appearance of a CARE tool rule change proposal posted in the biweekly Washington State Register. There, the public could view and comment on the proposed change, although the state governor would have the final determination of signing the revision of the rule change into law (Washington State Legislature, 1998).

There are a few steps in the process of trying to get state legislation to support a CARE tool rule change. The first step is to always find the desire and passion to bring up an issue to anyone involved in influencing state government lawmakers, such as an elected official within the State Legislature (Maryland & Gonzalez, 2012). If the elected official finds the issue important and is willing to listen to why the issue is important, the elected official can bring it up to their colleagues at DSHS, for example, to gain support on the issue (Maryland & Gonzales, 2012). If an issue gains enough support, especially from well-respected individuals such as nurses, the state governor may become aware of the issue and be influenced to consider the issue in favor of the groups in support (Maryland & Gonzalez, 2012).

Taking this into consideration, the policy change process can be long. The key here is to be patient when trying to enact policy change. Nurses have the capability to bring light to the CARE tool's hours per month allocation because it is often common for lawmakers to be unaware about healthcare policies (Maryland & Gonzalez, 2012). Therefore, it is up to nurses to stand up and say something about health issues because nurses see these issues on a daily basis in their practice.

Conclusion

Although the CARE tool is comprehensive in addressing care needs overall, adult TBI patients may not be adequately assessed for behavioral and cognitive care needs through the current use of the CARE tool. This is because both assessments require more information than what the current CARE behavioral and MMSE assessments can provide. The discoveries of other assessment tools, such as those analyzed previously, show that there are alternative methods which pay more attention to mild cognitive and behavioral signs and symptoms that could potentially require extensive care in the community over time. The current cognitive and behavioral assessments that are included in the CARE tool puts more emphasis on catching the behavioral and cognitive signs and symptoms that are immediately apparent at the point of discharge from the hospital setting. The current CARE tool also lacks the ability to consider psychological changes over time outside of the hospital setting, due to the nature of the cognitive and behavioral assessments included in the tool. The best way to go about changing the CARE tool behavioral and cognitive assessments would be through enacting policy change because the biggest stakeholders in this issue would be the elected officials in the Washington State Legislature and the Washington State Governor. Mental health is a big issue for the state of Washington that is frequently talked about in the media, and providing needed care to those with declining mental health is of utmost importance. However, Washington State Legislation will not provide as many state funded care hours to those with mental health issues as compared to those who have physical medical and mental health conditions together.

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