

VIEWPOINT



Early Shared Decision-Making for Older Adults with Traumatic Brain Injury: Using Time-Limited Trials and Understanding Their Limitations

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Abstract

Older adults account for a disproportionate share of the morbidity and mortality after traumatic brain injury (TBI). Predicting functional and cognitive outcomes for individual older adults after TBI is challenging in the acute phase of injury. Given that neurologic recovery is possible and uncertain, life-sustaining therapy may be pursued initially, even if for some, there is a risk of survival to an undesired level of disability or dependence. Experts recommend early conversations about goals of care after TBI, but evidence-based guidelines for these discussions or for the optimal method for communicating prognosis are limited. The time-limited trial (TLT) model may be an effective strategy for managing prognostic uncertainty after TBI. TLTs can provide a framework for early management: specific treatments or procedures are used for a defined period of time while monitoring for an agreed-upon outcome. Outcome measures, including signs of worsening and improvement, are defined at the outset of the trial. In this Viewpoint article, we discuss the use of TLTs for older adults with TBI, their potential benefits, and current challenges to their application. Three main barriers limit the implementation of TLTs in these scenarios: inadequate models for prognostication; cognitive biases faced by clinicians and surrogate decision-makers, which may contribute to prognostic discordance; and ambiguity regarding appropriate endpoints for the TLT. Further study is needed to understand clinician behaviors and surrogate preferences for prognostic communication and how to optimally integrate TLTs into the care of older adults with TBI.

Keywords: Brain injuries (traumatic), Decision making (shared), Prognosis, Uncertainty, Communication

Background

Although older adults (≥ 65 years old) represent only 10% of all patients with traumatic brain injury (TBI), they account for 50% of TBI-related deaths [1–3]. Compared with younger individuals, older adults with TBI have worse functional outcomes, more chronic psychosocial and cognitive impairments, and greater overall

mortality [2, 4–9]. These risks complicate the process of shared decision-making (SDM) after TBI in this population. Patients with TBI are often unable to express their wishes, so their surrogates must urgently make value-laden decisions about potentially life-saving treatment options on their behalf [10], frequently without prior conversations about goals of care. Reported rates for advance directives and/or established health care agents among patients with neurocritical illness range from 9 to 39% [11–13]. Predicting the eventual functional and cognitive outcomes of these choices is challenging early in the hospitalization, making it difficult for surrogates

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to appropriately weigh treatment options against one another [2, 14, 15].

Because functional recovery is possible but often uncertain [16–18], especially in the early phase post injury, interdisciplinary practice guidelines for disorders of consciousness caution against early withdrawal of life-sustaining treatment after severe TBI [19]. Similarly, the Neurocritical Care Society recommends an observation period of at least 72 hours before decisions about withdrawing life-sustaining treatments [20], and the Trauma Quality Improvement Program of the American College of Surgeons released Best Practices in the Management of Traumatic Brain Injury, in which the authors state that “the advocated best practice is to provide all severe TBI patients with a trial of aggressive therapy and not limit any interventions for at least 72 hours post-injury” [21]. Given the potential for neurological recovery, families and clinicians may opt for prolonged life-sustaining interventions, accepting the tradeoff that some patients may recover to an undesired life-state and possibly miss “the opportunity to die” [22, 23]. Recognizing the consequential nature of decisions made during this phase of care, expert committees have encouraged communication about goals of care very early after TBI. For instance, the American College of Surgeons Trauma Quality Improvement Program Palliative Care Best Practice Guidelines outline a time-based framework for communication tasks that should be completed within 24 hours and 72 hours of presentation, including “perform a prognostication assessment,” “hold a family meeting,” and “offer time-limited trials when appropriate” [24].

A time-limited trial (TLT) is an approach for managing SDM early in critical illness, including for patients with severe acute brain injury (SABI) [25–27]. TLTs provide a scaffold for decision-making by establishing a timeframe for treatment with objective markers for monitoring the patient’s clinical response. Such a framework may be helpful for managing prognostic uncertainty in early SDM conversations, while also allowing time for loved ones to adjust to the shock of the injury itself during this dynamic phase of illness. In this Viewpoint article, we discuss the use of TLTs for older adults with TBI, their potential benefits, and current challenges to their application in this population.

Time-Limited Trials: A Communication Strategy for Managing Prognostic Uncertainty

TLTs are useful to develop a treatment plan that accounts for a range of possible outcomes and aligns expectations for the patient, surrogate, and care team [28]. Table 1 outlines the communication goals of a TLT for an older adult after TBI, along with language that clinicians may use in practice. The framework of a TLT is critical for

structuring early management around three key elements: *specific treatments* (or procedures) are used for a *defined period of time* and with an *agreed-upon outcome* (or trajectory). Relevant outcomes after TBI may include signs of neurologic worsening (for example, no longer opening eyes to voice or loss of a brainstem reflex), or signs of improvement (for example, following a verbal command consistently or passing a spontaneous breathing trial on a ventilator). It is important to agree on specific outcomes that families may look out for, because not all changes in examination represent improvement or worsening. For instance, comatose patients will show spontaneous eye opening and develop day–night rhythm after a few weeks [29], and most patients will eventually regain the ability to protect their airway, so that liberation from a ventilator or tracheostomy does not always predict awakening [30, 31]. When looking for these signs of improvement, it is critical to also assess for other processes that may halt progress and confound prognostication during the trial, such as infectious or toxic-metabolic causes [19].

After agreeing on the timeframe and the outcomes to be assessed, clinicians and surrogates also agree on the next steps should the patient improve, decline, or remain the same at the end of the trial period [32]. Surrogates and family members are encouraged in the interim to reflect on how the patient’s values might align with any one of these potential outcomes and estimate how long the patient would want to be treated to achieve a minimum level of neurologic function that would make “life worth living” [33]. Although many SDM models focus on exploring past values and goals [26, 34, 35], it is essential to also consider how patient priorities may evolve to accommodate future life-states, a domain that is rarely discussed prior to injury [36]. Failure or success in meeting the outlined markers in a set period of time usually reflects a change in prognosis, which clinicians then communicate at the end of the trial [27].

Potential Benefits of TLTs

The goal of the TLT is to enable consensus-building between surrogates and the care team. Because TLTs are inherently negotiated entities, clinicians and families must come to an agreement about what treatments will be trialed, for how long, and to what end, which may facilitate open discussion about when these treatments are unlikely to succeed [28, 37]. Some have posited that TLTs may also offer potential psychological benefits to surrogates and family members [37]. For example, in qualitative interviews, clinicians and surrogates felt that TLTs allowed surrogates to define their own “best” and “worst” outcomes, by clarifying the patient’s goals at the outset and identifying realistic clinical outcomes [28, 37].

Table 1 Barriers to using time-limited trials for older adults after TBI

Communication goal	Possible language	Potential barriers
Define the acute problem and communicate prognosis Explain the treatment options, including potential risks and benefits	Most patients with this type of brain injury do not recover to their baseline Surgery to remove the blood clot could save his life, and maybe with rehabilitation, it is possible that he could get back to living at home, even with some difficulties. However, it is most likely that after surgery he will have persistent cognitive or functional deficits and will be dependent on others for his care and daily life, maybe permanently Foregoing surgery would allow us to focus his care on comfort, and he would likely die here in the hospital	Inadequate prognostic models Cognitive biases among clinicians during prognostication Uncertainty about functional prognosis or timeline for recovery after TBI
Elicit any known patient values or priorities Explore the surrogate's expectations and goals for recovery	Have you had any conversations with your father about his wishes if he were to get very sick? Based on what you know about him, what would you say your father's priorities would be, in terms of recovering from this injury? What do you think about the potential outcomes we have discussed?	Limited or absent advance care planning Affective uncertainty among surrogates about acceptable outcomes or levels of disability Prognostic discordance between clinicians and surrogates
Agree on a specific treatment plan Identify objective markers for improvement or deterioration	It sounds like your father would want us to go ahead with surgery, to give him a chance for a recovery that would be meaningful for him, including the opportunity to live at home and interact with his family After surgery, we will monitor him closely in the ICU for 2–3 days. We will see if he is consistently opening his eyes and following commands at the end of the trial. If it is difficult to arouse him, or if he is more confused by the end of the trial, those may be signs that he is getting worse not better	Variability among clinicians in interpreting neurological and other clinical findings Disagreement about the optimal clinical test to monitor and forecast recovery in TBI
Identify a timeframe to reassess prognosis and reevaluate the treatment plan	It would be a good idea for us to plan on meeting again after three days. Although it still may be too early for us to predict his long-term outcome, based on the evidence we have, this is the minimum amount of time we should wait before making any major decisions about the future [20, 86–88]	Insufficient evidence to define an appropriate endpoint for the trial period after TBI
Ask for initial preferences regarding subsequent treatments. Define potential actions at the end of the trial	If his neurological exam is the same when we meet again, we should weigh the pros and cons of continuing further artificial life support. Based on how he is doing, if we expect a long road to recovery, at some point we would have to consider whether all this intensive care would be worth it to him	Temptation among clinicians and families to continually defer difficult decisions and extend the observation period

The communication goals of each step in the time-limited trial (TLT) model are outlined here [27, 39], applied to the case of a frail 83-year-old man with a history of heart failure and vascular dementia, who was found unresponsive by his family after an unwitnessed fall

On arrival, he was somnolent but able to say his name. His CT scan revealed a right-sided, holo-hemispheric subdural hematoma with midline shift. Per his family, prior to this event, he had been living independently at home and had a daily caregiver to help with shopping, preparing meals, and managing his medications

The middle column illustrates language that clinicians may use to address these topics with surrogate decision-makers, drawn from existing strategies for breaking bad news, eliciting goals and values, scenario planning, and making a recommendation [4, 115, 118, 123, 124]. The column on the right describes the barriers that clinicians may encounter when applying the TLT model to older adults after TBI

CT computed tomography, ICU intensive care unit, TBI traumatic brain injury

As prognostic information is refined over the trial, surrogates may feel that they gave their loved one a chance to improve, while psychologically preparing for a bad outcome [32, 37, 38].

Because TLTs explicitly recognize that prognosis can evolve during the trial, medical therapies are viewed as components of an uncertain process that requires iterative reevaluation, rather than all-or-none commitments [39, 40]. Any response to therapies over the TLT may serve to decrease prognostic uncertainty at the next family meeting and contribute to a shared prognostic understanding between clinicians and families. Setting prespecified time limits encourages both parties to confront clinical uncertainty, rather than continually defer decisions to an “ever-more-distant future” [32, 40]. In semistructured interviews about TLTs, clinicians reported that conceptually outlining the patient’s early disease course as a trial period for specific therapies served as important preparation for a potential shift to comfort-focused care down the line (when appropriate) if those treatments failed to succeed [28].

Because the specific parameters of TLTs may vary widely depending on how individual clinicians employ them, measuring a meaningful effect on patient or family outcomes may be challenging in clinical trials, and the evidence to date is incomplete. One observational study suggested reduced health care utilization during critical illness in hospitals that deliberately used TLTs compared with those that did not [41]. This study used claims data to identify one “low-intensity” and one “high-intensity” academic medical center in the same state, and after observing clinical care and conducting qualitative interviews, the investigators identified that the low-intensity center used a default approach of TLTs for life-sustaining treatments [41]. Similarly, one quality improvement intervention involving communication training for clinicians and protocolled TLTs in the medical intensive care unit setting observed shorter length of stay and decreased use of invasive interventions without a change in hospital mortality [42]. Subgroup analyses suggested reductions of intensive life-sustaining treatments among patients with poor prognoses [42]. Further study is needed to evaluate whether any of these advantages are preserved when TLTs are used in the care of older adults with TBI.

Barriers to the Use of TLTs After TBI

Three challenges limit the effectiveness of TLTs when applied to older adults after TBI: uncertainty in determining and characterizing prognosis; cognitive biases and prognostic discordance during SDM; and ambiguity regarding appropriate endpoints for TLTs. Although these areas are problematic in all forms of SDM in critical illness [43], they uniquely interfere with each step of the

TLT strategy (Table 1), which may make it challenging to implement TLTs in practice.

Prognostic Uncertainty for Older Adults with TBI

A crucial element in beginning a conversation about a TLT is determining the prognosis of the acute injury and describing any uncertainty. Although older patients are at a higher risk of mortality and persistent neurologic deficits after TBI [44–47], there may be some groups (e.g., those who are a younger age, those without respiratory complications, and those with higher motor scores on the Glasgow Coma Scale) who respond well to aggressive measures [48, 49], which makes it difficult to predict neurological outcomes on an individual level. The dominant clinical prediction models in TBI are not well suited for older adults, as they often fail to consider premorbid functional status [2]. For instance, the Corticosteroid Randomization after Significant Head Injury (CRASH) and International Mission on Prognosis and Analysis of Clinical Trials in Traumatic Brain Injury (IMPACT) prognostic models overpredict and underpredict mortality among older adults, respectively, in part because these models were developed by pooling clinical trials and observational cohorts, many of which excluded older adults with preexisting conditions [50, 51]. Incorporating information on frailty may improve prediction of unfavorable outcomes among patients with TBI, regardless of age [52]. Some scoring systems have recently been designed for older adults with TBI, but these require external validation before they can be used to guide risk-stratification or management [48].

Cognitive Biases and Prognostic Discordance During SDM

The next step of the TLT strategy is to clarify patient-centered goals and expectations for recovery. Surrogates must judge whether any projected disability would be acceptable to their loved one [53]. Such “affective forecasting” is subject to many biases, including recall bias (i.e., surrogates may not accurately recall their loved one’s perspectives or abilities immediately preceding the trauma) and the “focusing illusion” (i.e., surrogates may underestimate the extent to which their loved one can accommodate to new disabilities, exaggerating things that will change) [54, 55]. Another common bias is “enmeshment,” when the degree of emotional overlap and relational closeness between the surrogate and the patient distorts expectations for the patient’s recovery [56].

Clinicians are also susceptible to flawed heuristics [57]. Well-known examples include anchoring, confirmation, and availability biases [58]; another is “ambiguity aversion,” when known risks are preferred to unknown risks

in decision-making [59, 60]. Clinician communication can also influence treatment decisions through “framing” effects, when the same medical information is presented differently [61, 62]. Clinicians have been shown to inflate their prognostic estimates after TBI, overestimating favorable outcomes for mild injuries and unfavorable outcomes after severe ones [63–65]. The latter risks therapeutic nihilism and “self-fulfilling prophecies” [60, 66, 67], in which downstream decision-making is constrained by early conversations, and life-sustaining treatments may be prematurely withdrawn [68–70]. There is limited observational evidence of how clinicians approach prognostic discussions for older adults with TBI [71], but one survey identified a wide range of beliefs, perceptions, and decision-making strategies for neurologic prognostication [72]. It is possible that these attitudes may influence decisions about early care limitations. Multicenter cohort studies have found that many patients with TBI experience early withdrawal of life-sustaining treatments within 72 hours [73, 74], earlier than guidelines recommend, so careful attention must be paid in future research to how these discussions are handled by surgeons and intensivists.

Discussions about prognosis are challenging for clinicians [34], and there can be wide variability in how clinicians describe prognosis [75]. In qualitative studies, families often report internal conflict about prognosis [76], drawing from a variety of sources (beyond the health care team) to navigate the decision-making process [77], including their intuition, internal belief systems, and prior relationship with the patient [78]. As a result, prognostic discordance between surrogates and physicians is common, including after SABI [79], with surrogates often retaining more optimism about the patient’s prognosis [77, 78, 80–85]. For patients with TBI specifically, clinicians and surrogates have reported contrasting views on the value of numerical prognostic estimates [14]. Miscommunication about prognostic uncertainty can influence treatment decisions and the recovery process: one recent study suggests that uncertainty after SABI fuels ongoing decisions to continue life-sustaining treatment and hinders the process of adapting to a “new normal” [13]. Open questions remain as to whether communication frameworks, such as the TLT, can bridge this divide between clinicians and surrogates during SDM.

Ambiguity Regarding Appropriate TLT EndPoints

The final key component of initiating a TLT is to determine appropriate endpoints for the trial, including a specific timeframe and objective clinical markers that can be used to reassess prognosis and inform subsequent discussions about goals of care. Professional societies in neurocritical care have recommended an observation

period of at least 72 hours for patients with SABI [20, 86]. Although critical prognostic information may emerge within the first 72 hours of intensive care after TBI [87, 88], the appropriate timeframe to monitor for neurologic improvement beyond 72 hours remains unclear. Neurologic status may take up to a year to plateau in older adults after TBI, and the mechanisms underpinning recovery of consciousness are only beginning to be described [1, 19, 89].

Methods used by clinicians for measuring and predicting neurologic improvement are variable [72]. Quantitative prediction models are often confounded by a lack of external validation with a high risk of self-fulfilling prophecy [90–92]. However, both the CRASH and IMPACT models for TBI have recently been externally validated with promising results [93], and in one study, they outperformed clinician judgment [94]. In qualitative interviews with physicians who care for critically ill patients with TBI (trained in neurosurgery, trauma surgery, neurocritical care, and palliative care), some suggested that using data from these models may reduce prognostic variability [95]. Nevertheless, large studies including older adults are still lacking, which means clinicians must also use other tools to make predictions for this population.

The optimal bedside assessment or clinical test to assess consciousness remains controversial. Clinicians may sometimes formulate and update prognoses based on a patient’s injury pattern and clinical characteristics, along with their individual experience with how similar patients fared in the past [66]. Evaluating wakefulness and awareness remains of central importance in forecasting recovery, including presence or absence of brainstem reflexes and cortical responses (e.g., localizing to painful stimuli or following commands) [96]. However, measuring and reporting examination findings can be subject to interrater variability [97, 98], and it is unclear whether frequently interrupting sedation for “neurological wake-up tests” identifies clinical information that would justify the additional physiological stress in the acute phase of TBI [99–101]. Coma and consciousness scales, including the Glasgow Coma Scale and the Full Outline of UnResponsiveness (FOUR) scale, may predict in-hospital mortality and poor functional states in the short term [102, 103], but there is a pressing need for measures that reflect meaningful, patient-centered outcomes in the intermediate-term and long-term.

Because of these uncertainties, it is not uncommon for families and/or clinicians to extend the trial, especially if unforeseen complications or diagnoses arise that were not discussed at the outset [28]. Without empiric data to define an ideal timeframe, the TLT may seem too long or too short [104]. Logistical constraints for clinicians, such

as rotating call schedules, may preclude them from taking ownership or seeing the trial to its conclusion [28]. Meanwhile, the “watchful waiting” period early on may be agonizing for surrogate decision-makers and families [13]. As a result, it is critical that the parameters of any TLT are documented and communicated clearly to all team members, and consistent messaging with surrogates and family is imperative.

Contending with the Limitations of TLTs After TBI

The exact timing and clinical parameters for a TLT cannot be prescribed generally and must be individualized for each patient, family, and clinical situation. One common TLT involves the decision to pursue tracheostomy, which often occurs 1–2 weeks post injury [105], and can be a value-laden decision point about continuing or withdrawing life-sustaining treatments after SABI [106]. Given that potential recoveries after TBI are expected on much longer timescales [107], surrogates may face internal conflict about such decisions, especially when uncertainty about functional improvement persists [23].

TLTs are indicated when the prognosis is unknown, the clinical status is dynamic, and the risks and benefits of treatment (in the context of the patient’s goals) are unclear. As information about the patient’s trajectory emerges during a trial, families and clinicians can weigh the probabilities together of a good or bad outcome, as defined by the patient’s values [33]. Ideally, further treatment choices are guided by the patient’s progress within this preestablished framework, rather than by biased perceptions of the clinician or the surrogate [104]. During this time, skilled communication by clinicians is key [76, 108]. This includes responding to the emotional needs of the family, which may supersede their informational needs [109]. For some surrogates of patients with SABI, the decision to continue life-sustaining treatment may not even feel like a choice when uncertainty grants a chance for recovery [106, 110]. For others, TLTs may offer support, allowing room for optimism while encouraging “shared deliberation” [111] about patient-centered, individualized time points when care limitations may be introduced [28, 110].

For TLTs to succeed for older adults after TBI, several system-level improvements would be helpful. First, surgeons and intensivists require better training in serious illness communication [112–114]. Although some communication models and frameworks have been introduced for this purpose [114, 115], further pragmatic trials will be needed to demonstrate their efficacy [42]. Training clinicians to use TLTs could potentially provide opportunities to mitigate framing effects (e.g., listing the advantages and disadvantages of each treatment option) [116, 117] and support scenario-planning (e.g.,

using a visual aid to illustrate best-case and worst-case scenarios) [118]. Second, greater attention must be paid to follow-up and survivorship in the current care paradigm. Clear documentation and communication of a TLT across the multidisciplinary care team is essential to allow for consistent messaging to family members and needs to continue in the outpatient settings. Such follow-up would need to include appropriate neurobehavioral testing at relevant time points [19, 119]. Equitable access to skilled rehabilitation should be available to all patients who survive hospitalization, so that the decision to continue or withdraw life-sustaining treatment is not influenced by financial means. Finally, some have advocated for increased flexibility in health care systems that would allow for “delayed” transitions to hospice, if a patient’s outcome at the end of a TLT is not in line with their values [13, 120, 121].

Conclusions and Implications for Future Research

Time-limited trials may provide structure and guidance to the SDM process for older adults with TBI, if clinicians are aware of their limitations. When initiating a TLT, clinicians and surrogates should discuss the acute injury and its implications for prognosis, agree on an initial treatment plan (after discussing the patient’s values and the risks and benefits of the available options), and identify objective clinical markers to monitor for a specified time until a scheduled follow-up conversation. This communication framework can help clinicians acknowledge prognostic uncertainty up front and develop a shared prognostic understanding with surrogates as the trial unfolds, so that their expectations are in line with the most likely outcomes. Critical barriers to successful implementation of TLTs after TBI still include intense uncertainty inherent to prognostication in this population, cognitive biases faced by both clinicians and surrogates during decision-making, and ambiguity regarding the appropriate clinical measures and time points for ending the trial. Improving prognostication remains an area of active research in TBI, and further study is needed to develop models that predict neurologic recovery and quality of life more accurately. Even if these become available, further investigation is required to better understand clinician behaviors and surrogate preferences for prognostic communication. As policy makers and payors incentivize high-quality geriatric care, the development, measurement, and evaluation of techniques for early SDM and prognostic communication will be essential for enhancing the care we deliver to older adults with TBI [122].

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