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Facilitating
Engagement in
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Facilitating Engagement When Faced with Challenging Patient Behavior

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The primary goals of neurorehabilitation after traumatic brain injury (TBI) are to support and facilitate recovery and to develop accommodative strategies that maximize function and quality of life. While the choice of a particular intervention is important, no therapeutic approach can be effective without full engagement by both patients and providers.¹ For some patients with TBI, engagement is threatened by neurobehavioral and contextual factors, requiring an especially intentional and thoughtful approach to maximize participation.

Engagement versus compliance.

Despite definitions of engagement that emphasize shared medical decision making,^{2,3} too often engagement becomes shorthand for compliance, or the extent to which the patient's behavior matches the provider's recommendations. Patients who accept treatment recommendations are seen as "engaged," and patients who do not are seen as "challenging." Engagement thereby becomes a patient-level variable, rather than a negotiated process that requires continual renewal "in accordance with shifting goals, expectations, and emotional needs."⁴

The problem with the engagement-as-compliance view is that when engagement fails, all efforts focus only on the patient. Moving away from this view requires an awareness that therapeutic engagement after TBI is both an iterative process and a two-way street. It requires providers to respond to a lack of engagement with curiosity rather than judgment, in the spirit of non-defensive, flexible problem-solving, and to consider their own role in the engagement process.

Engagement has a number of preconditions. At the most basic level, a patient must understand and remember what is being asked of them. They must believe that what is being proposed is the right treatment, based on a shared understanding of the diagnosis and target areas. They must believe that the work will translate to improvement in valued life areas, and not just improvements from the perspective of the provider. They must feel they have the resources (financial, emotional, cognitive) to do what is being asked. Finally, they must believe that the benefits of engagement outweigh potential negative consequences, which may be substantial.

In this brief article we will explore these preconditions in three TBI populations that clinicians often describe as challenging to

As many as 15% of permanent total disability claims through Worker's Compensation programs are related to TBI,¹¹ and TBI cases constitute 1/3rd of claims over \$10 million dollars.¹² The process of receiving worker's compensation for TBI typically involves an independent medical exam (or IME), which is a physician's assessment of the nature of the injury, ability to work, and need for treatment. Following treatment, a patient will eventually reach Maximum Medical Improvement (MMI), the point at which further improvement is unlikely. At this determination, a patient must either return to work or modified work, or consider other options for permanent disability. Their Worker's Compensation benefits are typically terminated.

The structure of Worker's Compensation programs can present significant barriers to engagement. Demonstration of impairment becomes inextricably linked to financial stability, and to a psychological acknowledgment that the injury occurred. A patient with TBI may thereby be incentivized to prove disability or to delay a determination of MMI. For some patients, getting better may actually be financially worse than not getting better, tipping the balance to cost over benefit. On the other side, providers suffer from the burden of more intensive and heavily scrutinized documentation, and may struggle with internal value judgments about the importance of work and productivity. It is no surprise that patients with TBI often describe an adversarial relationship with Worker's Compensation administrators, providers, and insurance companies¹³ typified by a lack of trust, perceived pressure to return to work too soon, and a sense that they are accused of "cheating the system."

The single most important thing a provider can do to improve engagement for these patients is to understand the Worker's Compensation system in their local setting. Providers are consistently rated as more helpful (an important feature of engagement) when they demonstrate a knowledge of the system and the impact of the system on the individual patient¹⁴ and offer help in navigating it. Provider skill in collaborating with the patient's claims representative can also directly influence the degree of patient participation in return-to-work programs.¹⁵

Providers should be aware of their own biases in working with these patients. Although rates of fraud and malingering in Worker's Compensation claims are contested in the TBI literature, the overwhelming majority of patients in the system (>80%) are not intentionally fabricating or exaggerating impairment. Conversely, stereotyping by providers can reinforce illness behavior and delay recovery in work-injured patients. Qualitative studies have shown that the attitude of a treating provider can influence whether a patient injured on the job feels the treatment is useful or important – an essential precondition to engagement.¹⁴ By learning about the Worker's Compensation system a provider may disabuse themselves of myths and notions that contribute to bias and limit patient engagement.

Summary

Engagement is a bidirectional process, and one that requires careful reflection and attention on the part of providers. Strategies to promote engagement focus on taking the patient's perspective, formulation of flexible and patient-centered treatment plans, a mutual understanding of treatment mechanisms, efforts to maintain rapport and trust, and management of personal reactions. While not every patient can maintain optimal engagement at every level of TBI rehabilitation, thoughtful identification of barriers to engagement can maximize beneficial outcomes.

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Author Bios

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engage: people with limited insight into their deficits, people with a functional or anxiety-related component to their cognitive impairment, and people with work-related injuries pursuing insurance compensation.

Patients with impaired self-awareness.

Poor awareness of neuropsychological deficits is a common correlate of moderate to severe TBI,⁵ particularly for injuries affecting the right hemisphere and cortical midline regions. These patients may see any impairments as overstated or unimportant, creating significant barriers to therapeutic engagement.⁶ Even when a patient understands what is being asked and feels they have the resources to do it, they are unlikely to see the treatment as correct, important, or worthwhile. They may see no value whatsoever in cognitive remediation and will find assessment tasks frustrating and unnecessary.

Reduced self-awareness after TBI should be conceptualized as an executive functioning deficit involving metacognition. Promoting engagement therefore is more strongly linked to providers and their interpretation of the behavior of the patient. Problems with executive function may be subtle, especially in the context of overt difficulties in memory and language, and may present as personality features. Providers may attribute poor patient self-awareness (and resulting lack of engagement) as lack of motivation, stubbornness, or defensiveness. Providers can easily fall into the trap of seeing these patients as “resistant” to their recommendations, thereby personalizing a lack of engagement, and making it worse. These misinterpretations will contribute to frustration, inflexibility, and a tendency to disengage. Early identification and provider knowledge regarding executive function deficits – including how such deficits can impact self-awareness – are essential. When executive function deficits limit participation, engagement is better served by active problem-solving and flexible compensatory strategies than by the assumption of low motivation or denial.⁷

Approaches for increasing self-awareness focus on enhancing a patient’s ability to internalize awareness and control over their behavior. Direct feedback about deficits and performance can be useful, when it is specific and respectful.⁸ While verbal/audiovisual and experiential feedback may initially come from the clinician, it is important to move quickly into opportunities for the patient to self-evaluate their performance. Tasks lacking direct connection to a functional outcome (such as word lists or puzzles) might be avoided, as the patient will experience them as a waste of time, and this burns rapport necessary to promote engagement elsewhere.

Should efforts to improve engagement by targeting self-awareness fail or plateau, a provider must let go of any personal need for patient concurrence. Rather, the focus shifts to an “agree to disagree” model, emphasizing shared, realistic patient goals that can exist regardless of severity of impairments, postponing unrealistic goals (e.g., return to driving, return to dangerous work), maintaining provider-patient rapport, and educating patient family members about executive dysfunction after TBI.

Patients with functional cognitive impairment.

On the opposite end of the spectrum from impaired awareness is the phenomenon of “functional” cognitive impairment. Often seen in cases of mild TBI or post-concussion, these patients are hyperaware of cognitive deficits despite reassuring injury characteristics and unremarkable testing results.

Although early models emphasized anxiety and trauma as primary driving factors, more recent approaches suggest a complex interaction of metacognitive processes,⁹ leading to a cycle of increased bodily scanning and symptom amplification. Importantly, even documented TBI with positive imaging can have a functional overlay if symptoms are markedly worse or more impairing than expected. The term “Functional Cognitive Disorder” (FCD) has been suggested for use in this patient population.

For people with a functional component to cognitive symptoms, problems may exist across all preconditions to engagement. Fundamentally, the provider and patient do not share a mutual understanding of what is wrong. A provider may see cognitive complaints as primarily the result of anxiety or poor coping, rather than brain injury. To the patient, deficits are subjectively real, and any explanation that they are not physiologic in nature can feel deeply unsatisfying and stigmatizing. Patients may also worry that their impairment represents a degenerative neurologic condition, such that time is of the essence. Unless this gap is narrowed, nothing a therapist recommends or attempts will result in patient engagement, since a patient is not likely to believe that a treatment based on the wrong diagnosis is going to help. This can result in a broken cycle of increasing demand for more or different treatments from the patient, fruitless attempts to meet this demand by the provider, and eventual burnout and disengagement on both sides. For the provider, it is essential to manage personal reactions to these patients, as visible frustration and disbelief are the enemies of engagement. Patients with functional cognitive issues are not malingering (this is a different issue entirely), and for them symptoms are real, distressing, and impairing. Maximizing engagement in patients with any functional neurologic condition starts with effective patient education.¹⁰ These patients typically do not benefit from traditional reassurance, such as repeatedly reminding them of normal test results or lack of diagnostic findings. Instead, a provider can provide an explanation that allows for the subjective experience of cognitive impairment in the absence of observed pathology. For example, one explanatory approach is a “bandwidth” model. In this model, a patient likely experienced typical neurocognitive symptoms after an injury (such as concussion). During the acute recovery period, they began to focus on symptoms and monitor them, perhaps at the urging of care providers. Although the initial injury healed, hypervigilance to symptoms continued. Over time, this scanning becomes more sensitive to minor errors and background noise, such that false alarms are constantly generated, reinforcing more monitoring. Continuous vigilance for symptoms is attentionally demanding, and diverts resources needed for daily cognitive tasks, resulting in a decreased ability to concentrate and encode new information. This is interpreted by the patient as evidence of memory impairment, leading to a cycle of worry and further scanning.

The purpose of psychoeducational models like this one is to emphasize that the patient’s cognitive symptoms are subjectively real, troubling, and explainable. This shared understanding can help the provider and patient agree on a treatment (for example, graduated behavioral exposure and attentional control strategies) that they can both support and engage in, while disrupting any argument about the legitimacy of symptoms.

Patients involved in Worker’s Compensation programs.

In the United States, Workers’ Compensation is state-mandated insurance purchased by employers to cover an employee if they are injured on the job.