Patient and Provider Reflections on Improving Care for Persistent Post-Concussion Symptoms

Featuring a Free Webinar
(also available as 1 credit-hour CME)
produced by Concussion Alliance
and the Med Learning group

A Patient-Centered Approach to Concussion Care
for Emergency Medicine and Primary Care Physicians

Conor Gormally
Patient Perspective

"I co-founded Concussion Alliance after experiencing several years of persistent post-concussive symptoms and not finding treatments through my medical providers. At this point I have had persistent symptoms for six years, although they now are more manageable."

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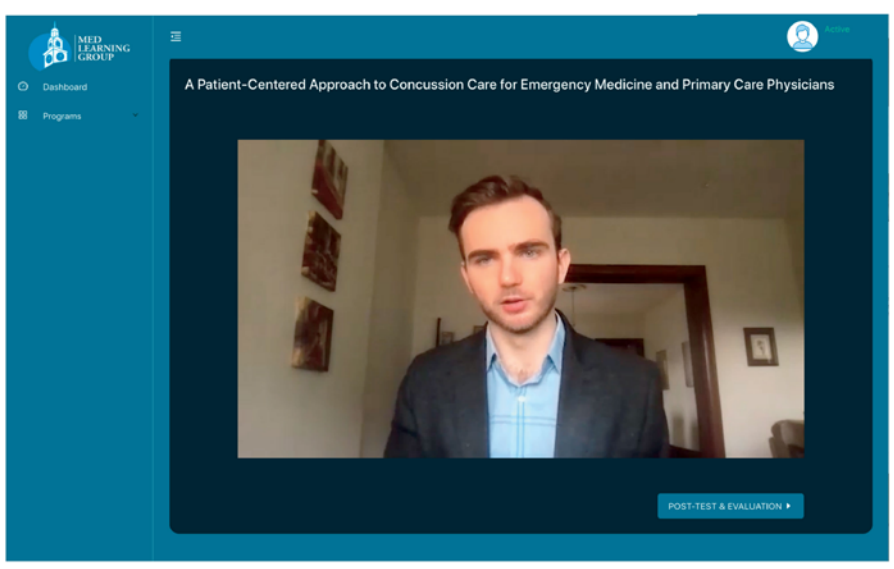
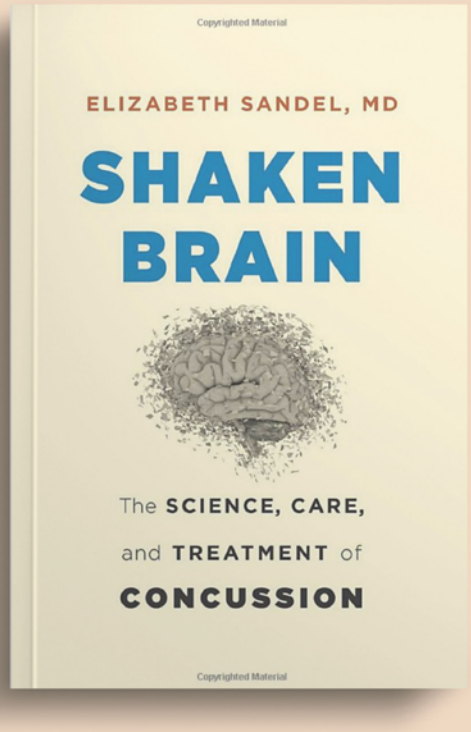
concussionalliance.org



Elizabeth Sandel, MD
Provider Perspective

"My career in physical medicine and rehabilitation and brain injury medicine spans almost 4 decades. I've worked with health systems and rehabilitation teams to set up concussion clinics in PA, NJ, and CA starting in the 1980s. Build it (using these up-to-date resources) and they will come!"

elizabethsandelmd.com

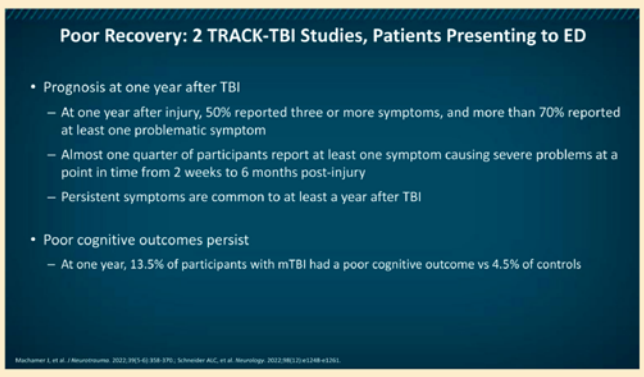


1.The Persistent Symptom Problem

Growing up playing soccer and watching the NFL, it was ingrained in me that concussion "wasn't a big deal" and people would recover quickly. Even though I took two months to recover from my first concussion, I still thought recovery was a given.

Six weeks out from my fourth concussion with no symptom improvement, my doctors still assured me that I'd make a full recovery and didn't mention persistent symptoms.

Patients lack education about mTBI/concussion and according to recent data from the TRACK-TBI study, emergency medicine physicians and other providers dismiss the need for followup for persistent symptoms after mTBI/concussion.



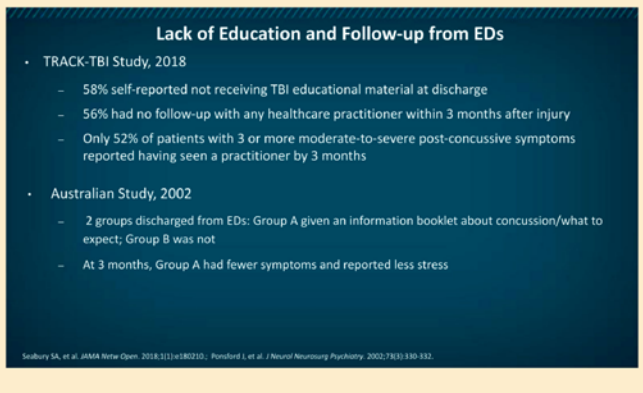
Persistent symptoms are more pervasive and active rehabilitation is more needed than most patients and providers understand

I know that the relationship between concussions and behavioral disorders is complex, and doctors don't want to add to patients' anxiety. Still, I wish my doctors would have prepared me for the (nontrivial) possibility that I might have some symptoms that would need treatment to resolve.

So many of the patients I talk to feel like there's something wrong with them because of their "failure" to recover on their own. We need to know that it's not unusual–common, even–for patients to need help recovering.

Patient-centered care honors the person and their family, respects individual values, and ensures continuity of care. Patients must be educated about their conditions–concussion or post-concussion symptoms–and provided with access to expert care and follow-up. Patient and family education must be tailored to specific needs identified at the initial and follow-up visits.

Health providers and systems must develop patient-centered systems of care based on focused examinations and targeted interventions. The percentage of patients with persistent symptoms is substantial; providers should build follow-up visits into the care plan until symptoms resolve.

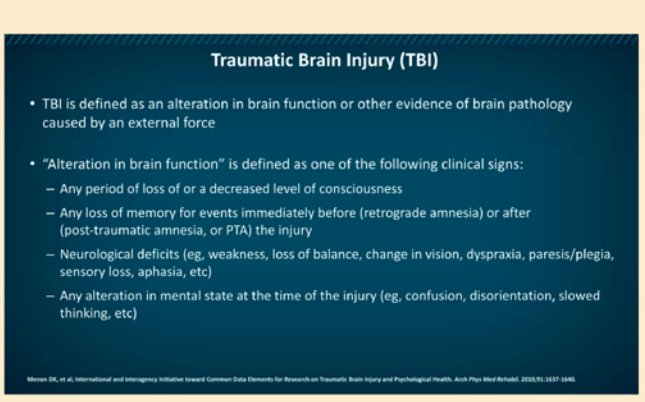


2. Definitions, Diagnosis, and Referral Issues

If I had known that concussion was a rehabilitative injury, my family and I wouldn't have felt so lost and confused, and I would've waited less time to get the treatment I desperately needed.

I wish the sports concussion clinic I went to for my fourth concussion had referred me to the outpatient rehabilitation clinic in the same building instead of a neurologist who diagnosed me with somatic sensitization.

For many decades, there has been a lack of consensus about definitions, diagnostic criteria, or coding systems for mTBI/concussion and post-concussion symptoms–which has caused confusion among providers, patients, and families and led to inadequate care that is not patient-centered.



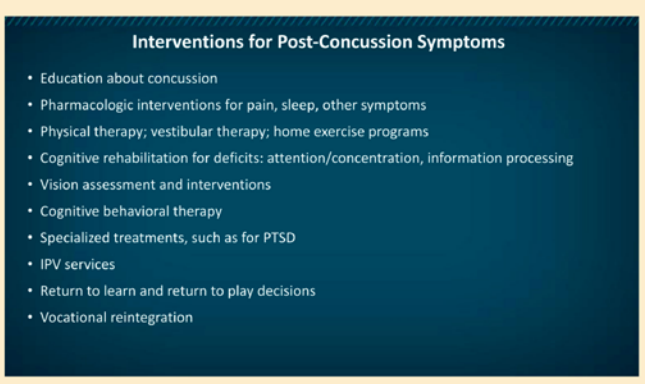
- Injury definitions are not unified
- Diagnosis isn't helping patients understand what's happening
- Coding and lack of knowledge is hindering referrals

Primary care providers must have a relatively up-to-date understanding of concussion and referral pathways. I wish that the primary care provider I went to for my first concussion had been more open to referring me to a specialist and hadn't leaned so hard on a suspected "depression" diagnosis.

Neither my primary care nor sports concussion clinic providers physically examined my head and neck or properly screened me for visual or vestibular dysfunction.

Many patients with a concussion history do not receive emergent, urgent, and follow-up care because of a lack of consensus about diagnosis and treatment and a tendency to dismiss these patients' symptoms.

The ideal clinical pathway leads concussion patients from an initial acute assessment to appropriate specialty referrals and focused interventions for specific symptoms and signs on physical examination. We recommend a rehabilitation team approach for those with persistent post-concussion sequelae and believe this approach can result in the best outcomes.

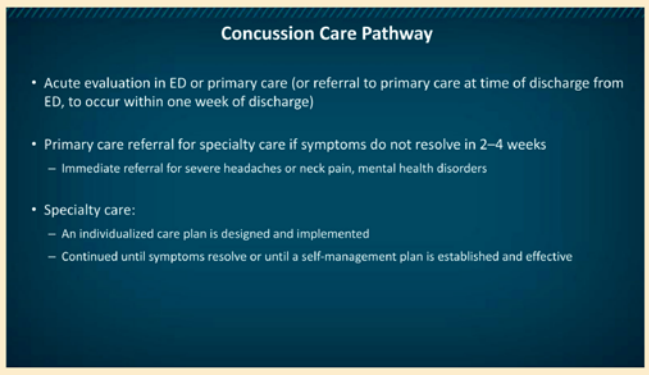


3. Our CME educates providers on a patient-centered care pathway

So many of the other concussion patients I talk to say they wish they'd had a "quarterback" to manage their care and get them to the right specialists. They, like me, had to figure out what kinds of specialists they needed on their own.

Primary Care and Emergency Medicine physicians can change patients' lives (like me) if they have the information they need to evaluate and refer properly.

Current consensus statements and guidelines do not adequately address best practices for evaluating and treating acute and chronic symptoms, referrals to specialty care, and timeframes for follow-up.



Patient-Centered Care requires changes at every level, but none are difficult to implement.

A better care pathway is possible if primary contacts know how to evaluate and to whom to refer to.

I felt like I was left in the dark during critical periods of my recovery after my concussions. If my primary care provider had been able to lay out a care pathway–like the one we built for the CME–for me, I wouldn't have lost nearly as much time and energy worrying about what was wrong with me and not knowing that I could do anything about it.

Education is immensely valuable for patients, and general practitioners are a critical first stop in many patients' care pathways; these providers need to know where to send patients next.

We offer many resources for providers to set up better clinical pathways based on patient-centered care, including our 1-credit-hour CME, our websites, and my book *Shaken Brain*.

Providers should use these resources to develop their own care pathway within healthcare systems for patients with mTBI/concussion–from the ED or PCP office with guidelines for follow-up and referrals for specialty care.

References: See our CME for references used