

Supplemental Material S1. TBI subreddit codebook.

Contents

Exclusion Criteria	2
code name: Exclusion.....	2
Post Author	3
Code name: Self.....	3
Code name: Other	3
Code name: Unspecified.....	3
Injury Severity	4
Code name: Concussion.....	4
Code name: Multiple concussions	4
Code name: Moderate-Severe TBI	4
Code name: Complex TBI.....	4
Code name: Unknown	4
Chronicity	5
Code name: Acute	5
Code name: Chronic.....	5
Code name: Unspecified.....	5
Concerns & Experiences	6
Code: About recovery	6
<input type="checkbox"/> Subcode: About return-to-school.....	6
<input type="checkbox"/> Subcode: About return-to-work	6
<input type="checkbox"/> Subcode: About return-to-life	6
<input type="checkbox"/> Subcode: Recovery Tips	6
Code: About symptoms	7
<input type="checkbox"/> Subcode: Symptom experiences.....	7
<input type="checkbox"/> Subcode: Psychosocial support for symptoms	7
Code: About medical care.....	7
<input type="checkbox"/> Subcode: Diagnosis	8
<input type="checkbox"/> Subcode: Medication	8
<input type="checkbox"/> Subcode: Treatment	8
Code: Other.....	8

Exclusion Criteria

code name: Exclusion

Definition: Posts unrelated to life experiences post Traumatic Brain Injury. A traumatic brain injury (TBI) is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force. Posts regarding nontraumatic brain injury, such as stroke, brain tumor, aneurysm, and neurological disease, such as Parkinson's disease and dementia, should be excluded. In addition, posts that only provide technical information, including TBI facts and statistics, summary of research findings, and study recruitment, should be excluded.

Example:

1. *"Unlike my brain injury mine was acquired through chemicals or drugs by a medication and supplement spice that I accidentally ingested a lot of."* (not TBI)
2. *"We are looking for people who are over 18 years of age who have experienced a brain injury to share your thoughts and experiences on using digital technologies to support your recovery."* (not related to life experiences)
3. *"Hi all, wanted to share our new podcast, Making Headway."* (technical info)

Post Author

Code name: Self

Definition: The post was created by someone who sustained a traumatic brain injury.

Example: *"I'm 1.5 years out from TBI."*

Code name: Other

Definition: The post was created by a caregiver, friend, or family of someone with a traumatic brain injury.

Example: *"A few weeks back my dad suffered a severe TBI."*

Code name: Unspecified

Definition: Information about the post author is unclear.

Example: *"Has anyone used Prescription "psychiatric" medication years out from their injury successfully?"*

Injury Severity

Code name: Concussion

Definition: The post describes the injury as a mild traumatic brain injury or a concussion. Suspected concussion falls under this category for further analysis. Alternatively, the post includes information about loss of consciousness (less than 30 minutes), alteration of consciousness/mental state (lasting less than one day), or neuroimaging results to determine the likelihood of a concussion.

Example: *"Hey everyone, I've been struggling mightily over the past few months with PCS."*

Code name: Multiple concussions

Definition: The individual who was described in the post sustained more than one concussion.

Example: *"I had sustained 5 concussion leading to many terrible symptoms."*

Code name: Moderate-Severe TBI

Definition: The individual who was described in the post self-reported a moderate or severe traumatic brain injury. Alternatively, the post includes information about loss of consciousness (over 30 minutes), alteration of consciousness/mental state (last over one day), neuroimaging results, or hospitalization to determine the likelihood of a moderate-to-severe TBI.

Example: *"I was hit by a car a year ago, and among other injuries I had some skull fractures and contusions in numerous areas of my brain."*

Code name: Complex TBI

Definition: The individual described in the post sustained a moderate-to-severe TBI and had a neurological history (e.g., MS, stroke, etc.) or a history of brain injuries, including concussions.

Example: *"Does anyone have any experience with getting a concussion on top of an existing Major TBI including partial brain removal?"*

Code name: Unknown

Definition: Injury severity was not self-identified; information provided in the post is not sufficient to estimate the injury severity.

Example: *"When I was 17 i had a serious head injury but was never tested for TBI."*

Chronicity

Code name: Acute

Definition: Acute means the most recent concussion, including suspected concussion occurred within one month before the post was created.

Example: *"I've suffered 3 concussions in my life, two mild ones and one significant one. Ironically the most significant one was the lightest symptom wise. I suffered my third a week ago..."*

Code name: Chronic

Definition: Chronic means the most recent concussion event occurred more than one month ago.

Example: *"I'm 3 months post-injury and finally back to things like work and exercise without issues, but I still have bad days. I'd like to hear some success stories to keep my hopes up!"*

Code name: Unspecified

Definition: The time of onset is not reported or unclear.

Example: *"I had a TBI at 23, now I feel stuck at 23."*

Concerns & Experiences

Code: About recovery

Definition: Concerns or questions about recovery course, family support, and impact on quality of life.

Example:

1. *"My question is how have others improved their symptoms? Are there any suggestions of things I can do at home to regain cognitive issues?"*
2. *"What are problems you experience while using screens?"*
3. *"How long has it taken you to recover from headaches?"*

- Subcode: About return-to-school

Definition: Questions, concerns, or experiences about return-to-school or school related activities.

Example:

1. *"I am a senior and I am not taken seriously. Any advice?"*
2. *"But i'm getting tired pretty fast after doing cognitive tasks like reading, studying, meditation and general brain stimulation."*

- Subcode: About return-to-work

Definition: Questions, concerns, or experiences about return-to-work.

Example: *"The last three I've been fired from for not being able to work fast enough and this current one I plan on quitting because my mental health has taken a severe hit."*

- Subcode: About return-to-life

Definition: Questions, concerns, or experiences about daily activities, participation in the community, and social life.

Example:

1. *"I was wondering if anyone has any recommendations for going to concerts or know if there are even any regulations that exist for venues to abide by regarding decibel levels, lighting/strobe effects, etc."*
2. *"I'm so sad about the whole situation, hard to have a social life, no desire to go out to the club or anything. It's just weird that I'm having this crisis after so many years."*
3. *"I'm having a real tough time with my friends downplaying what it's like for me to live with a TBI. Does anyone else deal with this?"*

- Subcode: Recovery Tips

Definition: Sharing of recovery stories and recommendations of things that may facilitate recovery.

Example: *"Decaf coffee has helped me feel more concentrated/alert/easier to retain memory. Regular coffee makes TBI symptoms worse. Coffee in general is great for the brain, I highly recommend."*

Code: About symptoms

Definition: Concerns or questions about symptoms, including validation of symptom experience, confirmation about the link between symptoms and brain injuries, symptom management and resolution.

Example:

1. *"I dealt with a foggy brain, dissociation, depersonalization, full body pain, just felt really really slow and a lot more stuff like fatigue and dizziness/nausea. I'm not sure if these symptoms will ever fully go away .. but any advice on how to handle this situation or thoughts on what's going on would be so nice and appreciated .."*
2. *"I was wondering how long after a tbi is your immune system compromised?"*
3. *"How long after your TBI did you still suffer cognitive fatigue? Other than taking 5 naps a day :(what helped?"*

- Subcode: Symptom experiences

Definition: Sharing of one's symptom experiences or post that seek management advice and ask what progress to expect

Example:

1. *"is this light sensitivity due to injury OR something else? Anyone experience this, too?"*
2. *"Sorry for sounding silly but how long until these symptoms go away?"*

- Subcode: Psychosocial support for symptoms

Definition: Posts that express distress after brain injuries and seek psychosocial support

Example:

1. *"Did anyone get worse and worse for a while and then eventually make a lot of improvement? I'm about 5 months post concussion and feel much worse than I did during the first month after the injury."*
2. *"I guess this is mostly for venting, although I would appreciate any advice anyone has. I just don't know if anyone can help."*
3. *"I have severe emotional regulation issues since the quote-unquote accident. I get frustrated extremely easily...I guess I just really want to say, hi. I'm not sure if I have any advice to ask for, but it might be cool to meet other redditors with brain damage stemming from physical abuse, or redditors with TBI/brain damage who also don't know a lot about their condition."*

Code: About medical care

Definition: Care seeking, medication, medical test, or medical treatment related concerns, experiences, and questions.

Example:

1. *"Temazepam and Lorazepam are the prescriptions, are there better ways? Something that actually makes me tired?"*
2. *"I'm all for trying the vestibular-ocular therapist, but I just wanted to ask if that's best start right now."*
3. *"I met 3 neurologists, an endocrinologist, cardiologist, a psychiatrist, did MRI of cervical, thoracic, lumbar spine, AND head. Numerous blood, hormonal and even STD tests. All of this happened in the first month. And the result was the dreaded by me words: YOU ARE HEALTHY. FINE. OK. WHATEVER"*

- **Subcode: Diagnosis**

Definition: Concerns and experiences in relation to diagnosis, including receiving and interpreting diagnosis.

Example:

1. *"I did go to a neurologist and had a CT scan. He told me that there was no visible damage and the chances of having had a concussion were slim. Does my event sound like a concussion?"*
2. *"I'm almost afraid to go to a neurologist because what does it mean if I'm actually brain damaged, would they be able to find anything all these years later?. Does anyone have any experiences with being diagnosed with TBI years after the accident?"*

- **Subcode: Medication**

Definition: Questions, concerns, or experiences about medication and supplements.

Example:

1. *"I'm curious to know what meds helped?"*
2. *"Has anyone had any success with anti-depressants or anti-anxiety? I'm pretty much anti-psychiatry to be honest. I don't have a mental illness, never have been diagnosed with one. I just don't like the label."*

- **Subcode: Treatment**

Definition: Any post content about treatment options and effectiveness, as well as barriers of receiving any treatment.

Example:

1. *"I've thought about therapy, but don't have that kind of money and fear what a doc my say about my freedom to go out as I like."*
2. *"Anyone tried HBOT ? Would love to hear some thoughts about it whether it's works?"*

Code: Other

Definition: Any concerns or questions that cannot be coded with predefined codes. Memos will be used to summarize the concern for secondary analysis.

Example: *"He's in a wheelchair, undergoing trach/speech trials, and really is still quite limited in movement. Not paralyzed, just still a ways to go in recovery. Can anyone suggest what would be a good and practical gift for a kid in this situation?"*