Interview: What is PTSD Really? Surprises, Twists of History, and the Politics of Diagnosis and Treatment

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Origins of the PTSD Diagnosis: Part 1—Medication Research
Let’s start with how the Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnostic system was born. It came out of a need for medication researchers to agree on a set of criteria so that when they studied a drug for, let’s say, depression, people in Los Angeles, New York, and Boston could have a common language for what they meant by “depression.” Its first incarnation was called the “Research Diagnostic Criteria.” At that point everybody seemed to agree that the mind is way too complex, and our knowledge way too limited, to conceptualize distinct diseases of the mind. But drug researchers needed to have a way of talking to each other to get a rough impression of which drugs work for different mental problems. And as crude criteria for drug research, they were serviceable.

However, the limitations of the criteria were well recognized. In the preamble to DSM-III, Robert Spitzer conveyed that the diagnostic system was way too inaccurate and schematic to ever be used for forensic or insurance purposes. That little preamble was left out of subsequent editions and soon psychiatric residents and psychology students came to be taught that the DSM diagnoses actually exist, that they represent concrete disease entities, rather than lists of symptoms. There was little talk that they did not have clearly identifiable, distinct brain or cognitive markers, that there was little research to identify the boundaries between disorders, and that there is an enormous overlap between these supposedly distinct disorders. Thirty years later, this situation has not really improved. After the simplest of field trials for DSM-V diagnoses, based on clinician ratings of written case histories, only five of the 23 DSM-V diagnoses have achieved scientifically acceptable (kappa) levels of agreement.

The Origins of the Posttraumatic Stress Disorder (PTSD) Diagnosis:
Part 2—Advocacy by Vietnam Veterans
The PTSD diagnosis was a result of intense advocacy and was created against huge opposition. As late as 1982 the opening line of a response to a research grant I had submitted to the Department of Veterans Affairs (VA) read: “It has never been demonstrated that the diagnosis PTSD is relevant to the mission of the Veterans Administration.” At that time the VA’s position was that the war had nothing to do with veterans’ pathology. The people who advocated for the PTSD diagnosis came from outside of academia: Vietnam veterans and two psychoanalysts, Robert J Lifton and Chaim Shatan, who wanted to create a diagnosis that was not stigmatizing. This meant that there had to be a diagnosis in which the symptoms were directly linked with the war experience. The centerpiece thus became Criterion B of PTSD: having “flashbacks and nightmares” about specific events. That linked the disorder to a particular set of traumatizing experiences.

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A Deeper View of What PTSD Is (and Is Not)

What’s interesting is that in response to trauma, what people really suffer from is not primarily flashbacks and such. I studied it from very early on, and what I heard people come in for, the chief complaints, were more:

– “Nobody is safe with me.”
– “I blow up at people.”
– “I can’t stand being with my kids.”
– “Noises drive me crazy.”
– “I hate my boss.”
– “I can’t sleep.”
– “I don’t take pleasure in things.”

All of these complaints have to do with being unable to be present and calm, being “out of it,” being overwhelmed by rage, and lacking meaningful involvement with their current lives.

In my research, I also started with flashbacks and nightmares. I happened to be interested in nightmares because the first research I ever was involved in was in a sleep laboratory, and the nightmares of the veterans I was treating provided me with a link to a topic I knew something about. So, we studied nightmares and REM interruption insomnia, but those were not the presenting problems of our patients. They usually complained about their uncontrollable violence and their lack of concentration:

However, as the anthropologist Allan Young has documented, the moment we created a diagnosis in which the B criterion was central, the veterans started to present more frequently with those symptoms because on some level they understood that they would get a better hearing if their complaints matched what the textbook of their doctors said. People’s clinical presentations adapt themselves to the prevailing cultural norms.

It’s important to remember that there were no field trials before the diagnosis was formulated, other than some informal compilation of symptoms of fewer than 200 veterans by Sarah Haley and Jack Williams, a small study of burn victims by Nancy Andreasen, and two excellent books: Mardi Horowitz’s description of Stress Response Syndromes (originally published, 1976), and Abram Kardiner’s 1941 book, The Traumatic Neuroses of War. Anne Burgess had already described a posttraumatic diagnosis, “rape trauma syndrome,” in the late 1970s, but without institutional backing that did not go very far. The criteria for that diagnosis were vastly different from those for PTSD and focused on shame blame and self-deprecation.

A Body Neurosis

Probably the most important inspiration for PTSD was Kardiner’s book, The Traumatic Neuroses of War. This described his observations of World War I veterans, whom he thought suffered from a “physio-neurosis”: Their bodies continued to react as if they were back at the moment of trauma and took the same physical actions that they made at the time of trauma, like blowing up, fighting back, ducking, or becoming frozen. So, the first view of trauma was as a body-based disorder—the whole organism is reliving, reenacting, and replaying the threat, and much of the initial research most of us did focused on physiology: biological systems that had gone awry.

Complex Trauma

Shortly after the PTSD diagnosis came into being, a group of us, including Judy Herman Jim Chu, and David Pelcovitz, noticed that there were other populations beyond veterans that had major trauma histories—victims of incest, child abuse, and domestic violence. Their problems had some overlap with those of combat soldiers, but they were different in that many of them had never developed the skills that soldiers had a chance to accumulate before their war trauma. These complex trauma patients lacked large aspects of normal emotional, cognitive, and neurobiological development: They dissociate, have major problems with chronic hyperarousal, somatization and concentration, and loathe themselves for what’s happened to them.
Our group focused on civilians with long histories of trauma that occurred in the context of interpersonal relationships. In those innocent days nobody claimed that they had the answers, and when we told Bob Spitzer, who then was still running the DSM-IV process, about the problems of this vast psychiatric population, we were met with openness. Bob Spitzer told us: “You see these people in your offices all the time, and I am just trying to figure out what clinicians need to make useful diagnoses.”

The American Psychiatric Association gave us $10,000 to do a study of over 500 patients at five different sites, comparing the symptoms of adults with acute trauma to those with histories of domestic violence, and a group with histories of childhood abuse. This was probably one of the first field trials where the diagnostic system was put to the test. We found that these three populations had very different symptom pictures, particularly those with childhood trauma, who suffered much more than the other two groups from self-hatred, amnesia, confusion, somatization, dissociation, amnesia, self-harm, and behavioral reenactments.

We wrote up our field trial and the PTSD DSM committee voted almost unanimously to create a second PTSD diagnosis called “complex PTSD” or “Disorders of Extreme Stress Not Otherwise Specified” (DESNOS). But the higher-ups in the DSM process vetoed the new diagnosis without giving us a reason, and with the disappearance of DESNOS this gigantic group of traumatized people lost the chance for a diagnostic home. Because studies are funded and conducted according to DSM diagnostic categories, it has been virtually impossible to systematically study the treatment of victims of domestic violence and child abuse, except under the rubric of their PTSD symptoms, which rarely are their most problematic issues.

Little Pure PTSD

I guess that, having done this work for about 40 years, I probably have seen as many traumatized people in treatment as anybody by now. I’ve seen thousands of them, but I have seen only a handful of cases of pure PTSD. Traumatized people often become alcoholics or drug addicts; they gamble; most have somatization problems; they are depressed and they dissociate; they have issues with eating and self-injury; they reenact their trauma. None of that is captured by “PTSD.” The Treatment Guidelines for PTSD nonchalantly suggest that if your patient has comorbid disorders besides PTSD, then you should consult the relevant treatment manuals for those conditions. That blasé recommendation may be fine if your principal concern is to keep your research lab going, but if your job is to heal your patients from their traumatic injuries, buying additional treatment manuals may not be the best way to restore them to a joyful and productive life.

The Myth of PTSD “Just Happening”

Another important point about the PTSD diagnosis is that it doesn’t usually “just happen” to people, yet it is often seen that way—you’re just driving along and somebody hits your car, or you walk along the street and somebody rapes you, and then you have PTSD. But, in fact, most trauma responses, particularly in women and children, occur in the context of intimate relationships.

In my very first study with Vietnam veterans, we looked at what preceded traumatic reactions in veterans. We found that they had started their military careers going to basic training, where they learned to become part of a powerful, self-confident fighting unit. They then went to war and continued to feel powerful and effective until a comrade was killed. Seeing a friend being blown away enraged them to the point that they often violated their moral principles and committed atrocities. Just as Homer wrote about in the Iliad, these were acts of revenge for the death of a friend, which set the stage for the recurrent reliving and reenactment of the trauma.

Trauma usually has much more of an interpersonal aspect than what the PTSD diagnosis recognizes. Ignoring this leaves out the vast majority of traumatized individuals. Most women and children are traumatized in the context of intimate relationships. Child abuse and molestation and family violence are all traumas at the hands of people who were supposed to love you.
Attachment

We are interpersonally connected creatures, and as children we are totally dependent on the beneficence and care of our caregivers. When the people who are supposed to make you feel safe also are the source of trauma, then you get a very complex set of adaptations. This is the case for a very large number of psychiatry patients who now have no “home” diagnostically. They show up as depressed, addicted, anxious, PTSD–you can call them any number of things. Indeed, in our work in the National Child Traumatic Stress Network, we find out that kids who get abused at home meet criteria for three to seven different diagnoses. I guess it is helpful that we have all these evidence-based treatments for every little diagnosis, but what is missing is the whole issue of attachment, betrayal, and abandonment, which interferes with normal developmental pathways. Our treatments almost entirely ignore what happens when trauma meets the attachment system. We do things because we are a part of tribes, communities, and groups. Yet the interpersonal dimension of trauma is being entirely ignored by the current paradigm that says, “You have a disorder and I am going to fix it.” This model totally de-contextualizes the interpersonal reality that people live in.

Treatment

As I said earlier, in developing the PTSD diagnosis, we had to link it to memory (symptoms such as flashbacks and nightmares) because if we had focused on other major symptoms—such as anger and the inability to feel pleasure and to be in the present–then the VA could continue to claim that PTSD developed in veterans because of their childhood or some genetic abnormality rather than in response to war itself. Criterion B became the point of entry so that people could say, “I am messed up because specific events continue to haunt me.”

As a result of the PTSD diagnosis focusing on memory-related symptoms, the treatments that were developed became focused on resolving traumatic memories. We seem to have some fairly decent treatments to address intrusive recollections, using exposure treatments and, if our studies are to be believed, even more, eye movement desensitization and reprocessing. But there has been a lack of focus on developing treatments that addressed the inability to concentrate and modulate affective arousal. In recent years, we have seen the beginning of attention to mindfulness techniques and neurofeedback methods to deal with those problems. But treatment research on how to deal with loss of attention, concentration, and engagement is still in its infancy.

Treatments Need to Fit How the Brain Works

In the early days of trauma research, there was intense communication between professionals engaged in psychotherapy, brain science, and neuroendocrinology. That decreased dramatically after colleagues started to assert that they had found “the treatments of choice for PTSD.” What is fascinating to me is that the first-line treatments that are being promulgated for PTSD are treatments that are orthogonal to what we know about how the brain works.

Neuroimaging research has shown that as people are reliving their trauma, the brain areas most involved in formal cognition are deactivated. So neuroscience research shows that when people are reliving, they cannot think rationally because the critical frontal lobe areas necessary for executive functioning go offline, and only the primitive fear, arousal, “my body’s in danger,” “I’ve got to run” parts of the brain light up.

So, the very thing that is needed—to think rationally—is wiped out when a person goes into the trauma mode. It’s like that movie in which a character says how great anger management training is as long as you don’t get angry. Sadly, the moment you get angry, all that learning that happens over in that rational part of your brain is not available anymore.

It’s been worrisome to me that we have not prioritized treatments that address the modulation of arousal states. On one end, people space out, disappear, feel nothing. And at the other end, people are hyperaroused and behave as if their life is in danger. These hypoarousal or hyperarousal states have nothing to do with our frontal lobe and cognition, which becomes
impaired when life events go outside of what Dan Siegel has called the physiological window of tolerance.

When we were invited to China, Japan, India, and Africa to deal with trauma there, I started to realize how much in Western psychology we value thinking by figuring things out and how much other cultures primarily emphasize self-regulation. For me and many of my colleagues, going to those places has helped us discover ways of regulating autonomic arousal by techniques like breathing, Qi gong, drumming, or yoga.

I have been surprised that something that is so obvious to me is not central in our pursuit of effective treatments: learning to regulate your autonomic arousal system is maybe the single most important prerequisite to dealing with PTSD. Physiological arousal needs to be calmed down before you can even access your executive functioning and the rational part of the brain. How people develop treatment techniques that are based on the premise that you can bypass this issue, and ignore what is going on in the basement, beats me.

I can’t help thinking that this can only be done if you don’t spend a lot of time seeing patients. But even without exposure to actual patients, you can see from the meta-analyses of the treatment studies that the overall results are quite disappointing. I may be becoming a curmudgeon, but when I interview post-docs, or listen to presentations by my colleagues at professional meetings, I detect a culture of: “This is the treatment of choice and if it doesn’t work with this patient, there either is something wrong with the clinician who administered it or with the patient.” I believe a clinically more reasonable and scientifically more responsible approach would be: “If my patient isn’t getting better, I need to learn something else to help them recover.”

I increasingly perceive that we are living in a culture of adhering to what some expert out there tells you is right for your patients, rather than trusting that what your patients tell you is helpful for them. We need to be careful not to create a world where actual clinical outcomes are divorced from what clinicians are taught. I hope somebody proves me wrong on that, because it’s an awful indictment of our field. Treatments in which patients’ PTSD scores drop from 65 to 45 are not effective treatments. They may have shifted people just a little bit; they are possibly a little less miserable, but given how much suffering there is and how much money is being spent, that’s not enough. Our job is to get people better.

One thing that can help us is to take what we have learned from neuroscience and apply treatments that incorporate how the brain works and is affected by trauma. One of the critical findings of neuroscience research is that the medial prefrontal cortex, the part of the brain involved in interoception—taking stock of yourself and noticing your internal processes—is the only part of the conscious brain with connections to the emotional brain. While that part of the cortex has consistently been found to be impaired in PTSD, the only way when you can get a hold of yourself and your physiological reactions is by activating that part of your brain and getting in touch with your internal sensations.

To become the master of your own ship you need to learn to modulate, deal with, and befriend your internal sensations. This has nothing to do with the lateral portion of your brain, which is responsible for understanding and explaining things—there are no pathways between that part of the brain and your emotional brain. To my mind, healing from trauma starts with noticing yourself and coming to terms with the sensations in your body.

The person who inspired that notion was Charles Darwin, who, in his 1872 book, *The Expression of the Emotions in Man and Animals*, brings emotional reactions back to the sensory experience transmitted by the vagus nerve, and registered in one’s chest and one’s abdomen. It looks like the principal way to learn to regulate your emotional life is to learn to regulate your sensory experiences deep inside yourself.

This doesn't mean that language is not helpful. The function of language is to be able to articulate your internal experience for yourself and for the people around you, and to establish a bond between you and other people. You cannot share your reality with somebody else until you put it into words. Being able to articulate things and feeling things very deeply and knowing what you feel is important. But it has less to do with exposing people than helping them to know what they know and feel what they feel.

So, for example, someone might learn how guilty in fact he or she feels about killing that kid, how they despise themselves for having raped somebody, for having been forced to stand
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by helplessly as somebody got blown up, how they let themselves down when they wanted to
do something—the helplessness of the inaction and the horror about the action. Those are the
things that we all want to run away from because we have to clean up what we did and what we
felt. But we need to accept everything that we know, everything that we feel.

What Is Needed in Research and Treatment

What is needed is some very serious outcome research that looks at who benefits from various
treatments and, possibly even more important, who fails to get better. Most treatment outcome
researchers seem to become wedded to their particular method, which they study over and over
again, in slightly different populations, under slightly different conditions, usually with the same
equivocal results. We should not pretend that we know the answers—we should leave that to
religious people.

When you look at the data, they are, by and large, disappointing. There typically is a 25%-30%
drop in symptoms, maybe slightly better than what we find when we give people placebo pills.
The question is: Are our patients really getting better, or do they just meet the statistical cutoff
for improvement? Until your patient says to you, “It’s over and I feel fully alive now” and is
joyously engaged in the present, nobody should claim victory.

This triumphant attitude of “we have found the right treatment” is especially misplaced for
victims of childhood abuse. I’m very concerned that students are taught to urge their patients to
talk about the most painful events of their lives without helping them to modulate their arousal.
That is obviously retraumatizing. Asking people to relive the most horrendous events in their
lives without teaching them how to feel safe and calm inside is hazardous to people’s health; it’s
so wrong.

Hypnosis

For about 100 years, hypnosis was the treatment of choice for PTSD. Yet very few clinicians use it
now to treat traumatized individuals. Hypnosis did very well with combat veterans in the Second
World War and the Korean War, but it disappeared because people came to associate hypnosis
with the implantation of false memories. What hypnosis may have been able to do (although
because that research is not really happening anymore, we only have the old data to go by)
was allow people to calmly let events pass by and integrate that into the larger memory system.
This is very different from brutalizing people by blasting them with the memories of trauma.
Desensitization is very different from integration and involves very different brain processes.

The Effect of PTSD Knowledge

It’s been disappointing how little effect we have had. That came to a head during the invasion
of Iraq. We knew what would happen from what we learned in Vietnam, Korea, and the First
and Second World War because this stuff has been studied for well over a century. Soldiers who
come back often suffer worse after the war than during. It was devastating that, before invading
Iraq, there was no concerted movement to warn about the price of doing that, nobody who
publically said: “We can send people to Iraq but that will mean that there will be more suicides
after the war than there were combat deaths. Because there always are. And they will commit
atrocities because soldiers always do. And there will be substance addiction because about half
of all people with PTSD develop addiction problems. There is so much that we know and that
we just choose to ignore every time we go to war. It’s been very disappointing how little effect
all this knowledge actually has had.

Key Message for Clinicians

The key message for clinicians is, first of all, learn to take care of yourself. Most people who get
interested in trauma develop that fascination because of traumatic events they have experienced
or witnessed in their own lives. So, see what helps you. Once you have discovered that, then you
can start applying some of these lessons to your patients. For example, we got into yoga because I discovered that I had lousy heart rate variability (low heart rate variability is also universally present in people with PTSD). Our lab thought that yoga might be able to change heart rate variability, and we discovered that, in fact, it did. But we discovered a lot of other things while doing yoga, as well. We now we have a thriving yoga clinic as part of the Trauma Center, and most of our clinicians are practicing what we preach.

Often clinicians ask me how they can get their patients to do yoga—they are so resistant. I then ask them: “Well, do you practice yoga yourself?” Most people say “no.” Are your patients not doing yoga because you’re a shining non-example of how you can be quiet and calm and mindful? If you look like a kind, warm, and integrated person, then your patient is likely to say: “I want to become just like you.” It’s an old tradition in psychotherapy: You start with yourself.

When you think about it, our diagnostic system is based on a strange paradigm, something like: “I’m healthy and you have a disorder and I’m going to apply this evidence-based treatment to you and after that you will be just as healthy as I am—disorder free.” In reality, of course, we fundamentally live in the same boat. As clinicians, we also have our issues with hyperarousal and shutting down and not being fully present.

So, maybe we should arrange to have therapy centers where the staff does the work on themselves first and then apply what they’ve learned about themselves to help their patients.