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Emotional Lability During Diagnostics Can Be a Normal Reaction to Abnormal Circumstances or Experiences in Leakland

Good morning, I'm Dr. John Reiman. I'm a trauma psychotherapist and a spinal CSF leak patient. I had two CSF-venous fistulas, one at T10-11 and one at T11-12, surgically repaired in 2022 after 14 months of life dismantling symptoms. My title today is "Emotional Lability During Diagnostics Can Be a Normal Reaction to Abnormal Circumstances or Experiences."

"Leakland" is often what I refer to as the global patient experience, from first symptoms through diagnostics, treatment, and recovery.

What is emotional lability? The whirlwind movement of mood, overall state, with associated rapid shifts of emotion. I think across Leakland, rapid shifts of emotion can be a constant, and I'm addressing particularly the front end during diagnostics.

A couple of caveats that are important on the front end. First, this presentation is clinically derived

both from and complemented by personal leak experience. Emotional or behavioral challenges that interfere with an individual's activities or daily living may invite referral for qualified mental health and diagnostic treatment services. I wanted to identify the role of seven different factors contributing to lability during the diagnostic period, although by no means restricted to the diagnostic period.

The first is the role of chronic pain on brain function. The prefrontal cortex regulates thoughts, emotions, and actions, and is the main center for critical thinking. Chronic pain patients often experience comorbidities such as depressed mood, impaired cognition, lability, etc. Also, given this diminished capacity, self regulatory efficacy seems to be reduced for spinal CSF leak patients.

The usual ways of managing stress and coping due to, I think, some of what happens relative to the brain on pain, are diminished to some degree. Next, the role of self blame and self criticism. Self blame is an interesting one here, and more broadly, in trauma, we find generally that people who have quite negative experiences or life circumstances, around which they had no control and felt powerless, they will often self blame.

And the logic behind the self blame actually makes sense. At least, if I can blame myself, I have some agency, some power, some control over something in a

process I otherwise don't have any with. There's also a piece here under self-blame and self-criticism of doing it "right," doing things "wrong," versus "doing the best I can," "being a good patient."

This gets confusing for people during the diagnostic period, because of course we want to be presenting our best self and be a good patient. But sometimes we don't have that sense. Guilt and shame seem to arise during the diagnostic period and are contributors to lability in that "maybe this is all in my head" is a refrain that a number of folks who are on this journey

end up experiencing at one point or another. And the last would be the role of self-compassion, which also seems diminished during the diagnostic period for a number of people. That self-compassion, I think, may be on board for people prior to entering Leakland and then be diminished. Others simply won't have it.

And self-compassion turns out, in the literature, to be perhaps the most critical factor for recovery from trauma and for treatment of depression and anxiety.

Next, the role of antecedent experiences. Emotional learnings from prior life events reside in memory networks, and unprocessed material in those networks can readily make the past feel like the present. So, experience in Leakland is informed significantly by history, by history of loss, history of illness, history of trauma, in addition to the moment to moment reactions to symptoms.

I would strongly suggest, and I know this is often done, that a trauma history be included in initial psychosocial workups. There also here is something I'm naming as individual differences. Meaning is assigned, not given. What that means is that when we experience something, we give it the meaning it has.

It's not assigned with the event. So, having a leak and having head pain, for example, may differentially be defined by us. One of us might be... having a self-referencing belief that "I'm weak" or "I'm helpless," in which case lability will probably increase. Some of us may assign meanings of "I'm strong" and "I'm resilient," in which case lability may decrease or not be quite as strong.

The role of tolerance for ambiguity. Defining this as the degree to which one is comfortable in circumstances and situations lacking certainty, clarity, definitive data, explicit steps, et cetera. For the patients who I treat in Leakland, and from my own experience as well, tolerance for ambiguity was key, because the shifting sands throughout the process are such that definition, certainty, clarity, um, they are elusive at times, so our individual tolerances for that will probably vary and inform the degree of lability we are experiencing.

Next, the role of locus of control and efficacy of self-advocacy. So I want to define here, internal locus of control is the belief that one can control one's own life. And the external locus is belief that life is controlled by outside factors beyond

influenceability. So what happens is, the greater the internal locus, the greater the self-advocacy; the lesser the hopelessness and powerlessness, the greater the sense of balance, and perhaps the lesser liability.

Also, distress seems to be, relative to the self-advocacy piece, associated with repeated failures to self-advocate. What this comes out to mean or look like is that patients in Leakland may go ahead and self-advocate and in some cases have that be efficacious and work. In other cases, may feel that it wasn't to their advantage to self-advocate,

and would basically reduce their self-advocacy efforts. People who have been in the diagnostic phase for extended periods of time, in my experience in treating these folks, will experience a diminished level of self-advocacy over time. It's sort of an attrition factor, but also, put crudely, um, feel like they're banging their head against the wall to no avail.

I realize that's an unfortunate metaphor here.

Next, the role of isolation and the absence of human resource support networks. Uh, in Leakland, it's a, it's a tough climb to find leak-informed clinical mental health services, mental health providers, who have some sense of what the, what the Leakland experience might look like. I think this is improving and increasing.

I know that I will on occasion network with psychologists or therapists who have not previously had experience with such patients, and now I'm able to direct them to resources, uh, even, even as they might not be able to open, to get it, they would have some increased sensitizing to the whole process, and I'm thinking that there's an improvement going on.

Speaking of improvement going on, peer support networks and social media, Inspire, Facebook, X, Twitter, et cetera, all really instrumental in bridging that isolation and increasing the support. And I want to just give a special recognition to the Spinal CSF Leak Foundation for making incredible progress on so many fronts in the area of support and of bridging out from the isolation that so many CSF leak patients experience.

I wanted to just touch on the role of inflated experiences versus emotional balance. This first one plagued me. I thought, "I'm a 70 year old guy, 30 years of clinical experience, I am better than this." And that wasn't a helpful cognition for me at all. Suffering and n— and feeling like my life was dismantled, I ran up against that belief and didn't find it helpful. I also know that I'm not alone in that. The other thing I want to note here is "ecologically correct." Having a leak is something that involves pain, involves a number of different symptom areas, symptom clusters, symptoms. And "ecologically correct" refers to just kind of the reality where, if I have a spinal CSF leak, I'm going to be experiencing different symptoms, and that the experience of those symptoms is ecologically correct, or correct to the ecology of having a leak.

In conclusion, and this is an important piece, this—and notice, not "my"— this emotional lability does not define me, even as it can be so globally consuming of my experience. Leakland can, for some, become a place where the personal identity one is used to gets hard to locate, because the symptoms obfuscate the

who, of who I thought I was, or who I thought I am. And so, I want to say that it's important that those providing professional support keep in mind and telegraph to spinal CSF leak patients that they are not their lability. They are not their leak, even as it can be so globally consuming in my experience.

I looked for a slide that might capture this. And, and this one features somebody where, where you could sort of see a struggle going on. And I wanted to bring in a light, not for Pollyanna-ish or syrupy reasons, but just because I think essentially reconnecting with that core of humanity that we each carry is important and can be challenging in Leakland.

Thank you very much.