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A How-To Guide for Young People*

Disinhibited Thoughts #19

Recently I presented at a Professional Development day for an Ontario school board. As I packed up my computer, one attendee whom I had noticed earlier approached me. Throughout my talk her face had betrayed her dubiousness in the positive message I was trying to confer, and so I steeled myself for a debate. Her forceful questions kept returning to the life course of TS: what were the odds of it going away? WILL it most likely stop? My increasing suspicions that this all stemmed from more than academic curiosity were confirmed when this woman abruptly burst into tears. She admitted that she had a son with TS and desperately wanted it to be gone so that he could enjoy a good life.

This incident reminded me of a mother of a TS child I know. Once, when I suggested that she may have a symptom of disinhibition or two herself (the whole “apple-not-falling-far-from-the-tree” phenomenon), she impulsively proclaimed “well how can THAT be! I function just fine!”. Ouch.

Situations such as these suggest to me that a fundamental confusion of the terms “symptoms” and “disorder” is taking place. They are not one and the same, but are often erroneously taken as such. Doing so inherently fosters further misconceptions – for example, the mistaken belief that medication is synonymous with treatment or, put another way, not medicating (suppressing) the symptoms is equivalent to not treating the disorder. It also leads to such counter-productive things as denial of symptoms and resistance to labels. After all, to admit symptoms is therefore tantamount to admitting that you are disordered and have a problem.

Is this a generational thing? A carry-over from times past where disorders, and the symptomatic, were shunned, not discussed, and hidden from society? Is it a by-product of the medical model, so pervasive in our world today? M.D.'s have lobbied for years to have the “marked distress or significant impairment” criterion removed from the diagnosis of TS given that, from their perspective, simply possessing the correct symptoms at the right times is sufficient to say the person has a disorder.

I don't quite have my head wrapped around it all, and I certainly can't speak for other generations or physicians, but it seems to orbit this idea of function being linked to symptomatology: my child CAN'T be happy, CAN'T do what (s)he wants to, my client WILL ipso facto be distressed and impaired and disordered, if (s)he has these symptoms.

Now hold the phone here: THAT suddenly sounds familiar. I've lived there myself. Growing up I denied the irrepressibility of my tics: TODAY I wasn't going to tic. At this DANCE I wasn't going to tic. I so badly wanted to stuff all of those symptoms deep down beyond detection because that, in my head, was synonymous with life being suddenly better. By not ticking I would now get along with my family. I would now be better at things. People would like me. GIRLS would like me. i would like me.....

How wrong I was. In fact nothing could be further from the truth, and this is one of the greatest lessons I could ever hope to impart. *Symptoms don't make a disorder.* People do. This was demonstrated by my Masters study where I measured the severity of people's symptoms, the degree of disorder present (through such measures as self-esteem, feelings of control in one's life, sibling interactions, and behavioural problems) and one's attitude towards the symptoms. *Symptom severity had no relationship with degree of disorder (i.e. coping success).* Attitude, however, had a great deal to do with degree of disorder. In other words, according to the results of my study a person with severely pronounced symptoms would fare better (and be less disordered) if (s)he had the right outlook towards the symptoms than someone with mild symptoms but a fatalistic approach.

We don't have the luxury of choosing whether or not we will have a particular neurology. Fortunately, though, we have more of a choice in whether or not we will have a *disorder* than many might ever believe possible.

Until next time, my friends!
B. Duncan McKinlay, Ph.D.
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