



Never be a Good Patient!

March 25, 2009 By [Richard Ferri, PhD, ANP](#)

I am so damn tired of this...I am **not** my fucking T cell count or viral load level and I wish to hell people would stop treating me like I am. It is degrading, and worse yet, it puts up a roadblocks to communication between friends, medical providers, and the rest of the damn world. And also please stop telling me how “grateful” I need to be to have to take life-long chemotherapy. I am over it. When you live with life-long puking, pain, incredible fatigue, and loose stool on a near daily basis then talk to me about gratitude.

I am not a fool. I have been practicing AIDS medicine since the beginning of the epidemic when all I could say to people is - “Get your affairs in order, Make peace with God and others, and tell me how much morphine you want me snow you with when you die?” Those were days of unbelievable horrors. I have a vivid memory of needing to do yearend report for a grant that I had to list the number of people that died of AIDS under my medical care over the preceeding12 months. The number was 642! I broke down in tears. Mainly because as I looked at that number and the list of names, and in my heart of hearts I knew I could not even recall the faces of 10% of the dead on that list. Today is very different and as a clinician I am a much happier man because of the advances in HIV therapy, but we have become a community that is still fixated on clinical numbers and not the person sitting in front of us and this had got to stop.

I recently felt compelled to change my AIDS doc because all I was a bunch of numbers to her. I was the “good” patient. She knew I took care of myself, was sober, worked out, and was nearly perfect with sticking to my meds. So I got the “greet them, treat them and, street them” kind of medical care all clinicians fall into now and then on a regular basis. So after numerous attempts of talking with her about my care concerns and not seeing things change I said the short version of the Serenity Prayer, which is “Fuck it!”, and found another provider who is wonderful. She treats me like a real person. *I am a real person!* She asks what is going on in my life and my numbers, while still important, are not the heart and soul of every visit.

Just because I happen to be HIV positive myself does NOT mean I am a “perfect” HIV medical provider because I am not a “perfect” person...as it says is in the AA Big Book....Progress Not Perfection. I screw up in my life, my clinical care, and just about anything I get involved with - I think it is called being human.

However, clinicians that look at my numbers and NOT us are not doing their job. I have had several other medical conditions overlooked because of my being a “good patient” that I had to handle myself. But I am lucky because I am an AIDS certified Nurse Practitioner and knew how to get the help I needed. What about the average person with HIV/AIDS without that sort of background? What happens to them? I assume they fall through the clinical cracks and suffer. This is bullshit.

Maybe that is the lesson here: NEVER BE A GOOD PATIENT!

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