

## Nonadherent: A Four-Letter Word

**D**o you have any idea how frustrating you were? You refused to take certain medications; contested every blood draw; limited all your responses to “yes,” “no,” or “I don’t know.” Nonadherence in the form of missed dialysis appointments was the reason that you were admitted to the hospital in the first place. Don’t you realize that? Why do you refuse to take care of yourself? Do you not trust us? Do you not care?

And who was that strange man who delivered a “package” to your room and told you that next time you have to pay for the gas money? We know that you have a history of cocaine use. Are you doing street drugs in the hospital? Is that why you are always so drowsy and noncommunicative?

Your self-constructed roadblocks were worse than a disease with an ever-elusive diagnosis. At least in those cases we are given an opportunity to find a remedy . . . if we fail, then it’s on us. But with you, you shut the door and there was never a real chance for success.

At least that was how I felt during the first several days of caring for you. Every morning, I tried to get you to communicate with me. I leaned over your bed and asked why you declined some of your medications. That was always met with a shrug. I explained what the medications were for and why they were important. You sleepily nodded in your defiant way, like a teenager does just before turning his back to an authority figure and rolling his eyes.

But one morning, you whispered an apology for being difficult. I started to wonder if you were just in too much pain to communicate, or if you were too exhausted, or if we were doing this to you through our pharmacologic wizardry . . . or, still in the back of my mind, if you were on drugs that we were not giving you.

On day six, I got my answer. I walked into your room and was shocked to find you sitting up in bed. You made eye contact with me; you smiled. You have a nice smile, you know. You told me that your pain was gone and that you felt like a different person. You acted like a different person, too.

I went through our usual morning routine of asking why you declined some medications, but this time you answered. You did not want to take them not knowing what they were for, and you were too ill to understand what they were for. You are not yet sure that you want to

continue antiretroviral therapy because you feel like your day revolves around scheduled pill-taking.

You told me that you have been HIV-positive since birth and that you lost both your parents to AIDS. You have no friends and no social outlets. You are younger than I am, coping with all of this, practically alone. Your only support is your cousin and godmother. You cannot work because of your many health problems, and this adds to your isolation.

You feel inundated by all of the medications, the doctors’ appointments, the “shoulds” and “should nots” that accompany your illness. You have contemplated suicide in the past—that is when you do cocaine—when you feel so low and so overwhelmed that the only escape seems to be drugs or death. You tell me that you have not done cocaine or other drugs in 3 months. I believe you.

You say that there must be a reason that you have made it this far. I agree. You want to make the most of your life. I applaud you. As you wipe away tears, you apologize for missing dialysis and explain that you were just too sick to take the two buses to get there, go through with it, and get back home on your own.

I apologize, too. Not out loud, but from somewhere deep inside where I feel tremendous guilt for being so frustrated with you and so unfairly critical. “I am very, very sorry,” melts out of my heart, makes a lump in my throat, and threatens to run down my cheeks. I do not know what decisions you will make for yourself in the future, but I now understand the decisions that you made in the past.

You did not refuse to give us an opportunity to treat you. You instead reminded us that the will and desire of the patient should be the central aspect of any treatment plan.

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