Compliance and Recovery

Gareth Fenley

Medication compliance is a goal of psychiatric treatment, according to many psychiatrists. It seems obvious to a lot of people that this makes sense. Family members, especially, who see a loved one drowning in a sea of unseen troubles tend to grab quickly onto this life preserver. It is the easy answer.

It is also an uncommonly achieved goal, as all of us who have gained experience in this field know, whether we are paying to receive the prescriptions (as I do), writing them, or witnessing the process in our families, cajoling and sometimes despairing. Perhaps this problem is so intractable because medication compliance is seldom a goal shared by the patient, at least at the outset.

This was clearly demonstrated at a psychiatric research presentation I attended. A study coordinator introduced one of her subjects who had agreed to speak, glowingly announcing: "He is 100 percent medication compliant." The man described an impressive story of salvaging a wrecked life. Thinking that I, too, would feel proud if I had contributed to his apparent success, I wondered how he saw it.

"What are your goals?" I asked.

He answered immediately and emphatically: "To be off medication. To be normal. To be free."

I wondered how these goals could be reconciled with the study's worldview. In terms of his own targets, he seemed completely off the mark. He was standing in an office building in bare feet.

I know too well from my own personal experiences that psychiatric medications can help tremendously with the effort to build what seems like a normal life or can actually undermine it, depending on how their powerful effects impact body, mind and spirit. It's most discouraging when medications help and hurt at the same time. The family and doctor see improvements, but the patient can't tolerate the situation, and quits the meds.

In truth, medication compliance should never be more than an objective, not a goal in itself. Medication is one of many tools in the kit that we can all use to move along the lifelong path of recovery in psychotic disorders. By framing treatment in this way, I can direct my own recovery, even if—especially if—I hope to go off meds in the future, while guided by my doctor's best clinical judgment.

Of all the entries in the journals I kept after my psychiatric hospital release in 1997, the one that is most poignant for me is dated July 22nd. That evening, I wrote about how it was a "sad choice" to be "voluntarily restrained from that lovely madness."

Years have gone by, and I have answered the question I had not settled for myself in 1997: Do I have a mental illness? Six months passed, then nine months, then a year, and now there has been more than a decade since what my first psychiatrist called "putting my brain in a blender." Today I can answer that yes, I do have a mental illness. I know I really do. I've been convinced completely without a doubt that it involves brain chemistry out of whack. My troubles are not limited to that, and I can't just fix everything with pills—certainly not—but I need the pills for the chemical side of it.

Also, I have finally reconciled myself to the persistent psychotic aspect of my illness, and I am resigned to taking antipsychotics indefinitely. I've been trying to get off them since I first realized what they were, and that strategy does not work for me. Actually feeling that I want to take them is a fairly new development, but even that motivation ebbs from time to time.

Let's be frank. The bottom line is, despite how cheerful I can be about it, I hate taking meds. I'm in a sour mood about them right now. I hate the expense, the hassle, the intermittent humiliation. No matter how much I grow used to the routines involved, it seems there's always something upsetting the apple cart. Most of all, I hate what they mean, these pills they call "crazy meds"—the dependency they imply and the stigma they ensnare. To agree to take them is a concession to weakness, I sometimes think when I'm in a rebellious frame of mind. All this needs to be accounted for in my dynamic relationship with my prescriber if I'm to continue to follow through on the plan set in each appointment.

As my colleague, Alex Mabe, notes in our collaborative presentations for Project GREAT (Georgia Recovery-Based Educational Approach to Treatment), Patricia Deegan and Robert Drake have argued that the notion of compliance is rooted in a paternalistic tradition of medicine. This old-fashioned model is at odds with the newer principles of person-centered care and evidence-based medicine. Deegan and Drake suggest that the compliance model, with its emphasis on medical authority, is

too simplistic to address what is really going on in my thoughts and actions. According to these authors, I go through active, complex decision-making processes to discover what I personally find to be optimal use of medications in my quest to achieve recovery.

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Inherent in the recovery model of mental healthcare is a move away from compliance (or adherence, a term switched in to make the same concept seem less coercive) and toward shared decision making. As Deegan and Drake explain, this entails a process of collaboration to arrive at a mutually acceptable plan for moving forward in the treatment process. Shared decision making involves two experts: one who knows the scientific literature and has clinical experience, and one who knows his or her own preferences and subjective experiences.

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In other words, when I am in the patient role, I am the expert on myself. I work with a mental health professional as my consultant whose role is not to enforce or ensure compliance, but rather to teach me and guide me in choices. My doctor makes recommendations, and I make the final decisions. That's what is meant by the shift from compliance to alliance. It's a change of paradigm, not a euphemistic change of words.

In order for psychiatric medications to be used more effectively on a mass basis, what this society really needs is a movement that will show them to be agents of freedom rather than zombiehood. We need to take a cue from people who are no longer "confined to wheelchairs" but who are now described as using wheelchairs for mobility. Pharmaceutical companies may run endless ads with sunny landscapes and hopping happy faces, but it's the pharmaceutical customers, people like me and Pat Deegan, who must "come out of the closet" publicly in ever increasing numbers to change what it means to use psychiatric medication.

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Deegan PE, Drake RE. Shared decision making and medication management in the recovery process. Psychiatr Serv 2006;57(11):1636-1639.