

Clozaril - The Miracle Drug: What are Doctors So Afraid of?

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INTRODUCTION

When I was diagnosed with Bipolar disorder in 1995, I was initially prescribed only Lithium. For me, it was like taking water, nothing changed. I remained manic, experiencing hallucinations and delusions. In a normal human being brain waves travel in a straight line, but in those of us who suffer Bipolar Disorder or Schizophrenia, they go haywire.

My second doctor prescribed Risperidone. The hallucinations ceased, but it felt like black tar clogged my brain. I thought to myself, "If I have to live with a mind like this, I don't want to live anymore." Perpetually manic, I have never experienced depression. That is why I can address mania better than most. Too, I've learned through the years, while doctors have never experienced what those of us with sporadic brain waves are suffering, it is appalling how little a few trust their patients. Many of us are college educated. I, for one, am a former auditor with a gifted I.Q. so feel I am fully capable when it comes to assessing the drugs doctors have prescribed me.

Going through a divorce, I had to work, but knew I could not focus well enough to return to auditing. I took a job working security at the George Bush Intercontinental Airport in the International Building. On Risperidone, my mind stayed clogged and in its lowest lobe where I couldn't focus. When we were on the machines, the FAA and our boss slipped bomb simulations, tiny wiring and so forth, through when we weren't looking. If I missed any bomb parts, that would have cost me my job. So, to focus, I learned I had muscles in my brain that I could push upward with. Only on Risperidone can I feel these muscles. So, I would push, push, and push until I entered the upper lobe where I could concentrate. Then, afterwards, I would be so tired, I just let go and found my brain clogged with black tar again. I would be sitting on the gate and more people than I can count would pass and go, "Smile," but I would just think to myself, "I don't feel like smiling".

Seroquel came next. My mind went blank, literally. My only thought was repeatedly, "I can't think! What am I going to think about? I have to think, but I can't think!" My brain refused to shut down entirely so I could rest it, yet no thought what-so-ever entered. It made me crazy. So, I began to count. I slept as much as I could, but found myself awake at 3 am. As a result, I was forced to get on disability.

Thanks, be to God, my brain did a 360 when I was asked to participate in a 3-year study on Clozaril, headed by Doctor William Rogers at the Andrews Center in Tyler, Texas. I need to emphasize I was on the actual Clozaril, not the generic Clozapine which acts differently with me, though I am the exception, not the norm. For the first time in my life, I felt normal again. I met with a psychologist two or more times per week, answering his four to five-page questionnaire, then Doctor Rogers grilled me. On 500 MGs, for the first few hours Clozaril made me incredibly drunk, so I took the med before bedtime. By morning I felt great, my formal self before mania. My current doctor, Dr. Steven Danley, gradually lowered my dosage to 200 MGs and we found that was not only all I needed mentally, the side effects disappeared. If I woke during the night, I now longer experienced

the drunkenness. Constipation disappeared. Around 1 pm I was no longer lethargic unless I ate and a little coffee took care of that. Now, I alternate between 100 MGs and 200 MGs, nightly. Any night I don't take my meds, I don't sleep.

Clozaril carries a stigma with doctors and I've tried to learn why. Patients are required to get first weekly, then bi-weekly and finally monthly CBCs, but believe me, it's worth the effort. I have been on the medication for more than 15 years and not once has my white blood cell count been low. Because the low blood cell count frightens many doctors, with the test they will be alerted should that happen. Myocarditis occurs in 1% of patients. It is recommended that ECG controls be monitored for the first four weeks of use. Tachycardia, a fast pulse rate, occurs in 25 out of 100 patients. Drugs are available to treat this. I have never experienced either. For me, personally, my blood pressure has always been slightly low and has remained constant through the years. Unfortunately, few pharmacies carry Clozaril. Most say they are not approved to do so. I must drive 15 miles to get mine, but there again it's entirely worth the effort.

When Doctor Rogers left Andrews Center after the study, the new doctor I was assigned refused to prescribe Clozapine. Calling him daily, I told him I hadn't slept for four weeks on Zyprexa. I explained the lack of sleep drove me to hallucinate. He prescribed sleeping pills! Of course, for someone manic, they didn't work. The hallucinations became so severe I was unable to get out of bed. He treated me as though he was the educated doctor and I was the crazy who would always be ill, so flat refused to listen to me when I begged for my med. Not only that, he worked at Andrews Center during the study! At first I was told I couldn't get a different doctor, but ultimately learned I could.

I told my new doctor, and current one, Dr. Steven Danley, that only Clozaril worked in my case. So, he said simply, "Then, we'll put you back on Clozaril." The pharmacist filled it with its generic Clozapine. Insurance companies require pharmacist to substitute the generic. Unlike most patients my body reacts differently to Clozapine. I do not want doctors to rule out Clozaril should this happen to a patient. Twice I tried Clozapine and experienced the same reaction. Whereas Clozaril brings me down from a high, Clozapine did right the opposite. I was in Walmart, after taking the drug the previous night, and could not even walk I was so high. I felt as though my brain was filled with electricity. I was wired. Everything was in a white zone. I had to drive home at a snail's pace on the side of the road with no ability to focus. On that occasion, I called my pharmacist and he said, "I'll do the paper work to get you your Clozaril, immediately." After one night, I was back to normal.

On the day I learned my father, who had a stroke, had to live the remainder of his life in a nursing home, it threw me over the top. As with any manic individual, I stopped my medication. That resulted in an altercation in a service station, whereby the police took me to a mental facility in Longview, Texas. My daughter, who lives in Los Angeles, couldn't find me. The police and every mental institution in the state told her the law prevented them from revealing my location. This is a terribly frightening for both the patient and the family. Frantic, she came to Texas and searched for me for more than two months, taking a leave of absence from work. I had no extra set of clothes or money. Finally, someone broke that law and told her

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where I was. She immediately contacted my doctor and told him that Clozaril was the only medication that worked for her mother.

Still he refused. I was suffering delusions, no hallucinations, but when I did finally see my daughter, I thought she was an imposter, bless her heart. I told both doctors that I had been in a 3-year study and only Clozaril worked for me. I explained that for me, personally, Clozapine had the opposite effect. I revealed I had tried a multitude of drugs, but apparently, some doctors don't believe their patients know what they are talking about. Why won't they listen? The patient is the only one who knows what he or she is seeing and hearing; what works for them and what doesn't. That's not to say all doctors are bad, I have had more good ones.

That doctor tried every med on the market. He prescribed three different medications simultaneously, including Olanzapine, Zyprexa and others I don't recall, while giving me daily shots. He switched drugs three times, all the while with me exclaiming, "Only Clozaril works!" Christmas was only a week away. My daughter was told since the facility was private, Medicare patients had to be released to allow room for paying patients when the facility was full and the facility was full. She asked to be contacted when I was released, but they told her they couldn't do that. So, she asked what the procedure was and was told, "The patient is removed from the facility and let out in town." She immediately went into panic mode. I live more than 40 miles from the institution and had no phone or money. At that point, she contacted my doctor and threw a fit. She screamed, "Clozaril is the only medication that works for my mother! You either prescribe it, immediately, or I'll see you in court tomorrow!" He was a nice guy, but for some reason feared Clozapine. I had been in that facility going on three months! On week-ends I had a different doctor, but he refused Clozapine as well. Finally, after my daughter threw her hissy, I was allowed my med. The very next day I was in a perfect mental state. The doctor held me another three, though. My daughter was never notified I was being released, but I called a friend to come and get me. Doctors, please fight for compassionate laws.

Once I was out of the hospital, and back in Doctor Danley's care, I explained my stay in the mental facility and he was utterly shocked the psychiatrist refused to provide Clozaril. He asked, "When you told him only Clozaril works, why didn't he prescribe it?"

I said, "Doctors do not believe mental patients!" Too, I had told the doctor to consult with Doctor Danley, who had been my Psychiatrist for nearly five years, but that never once occurred.

Dr. Danley appeared troubled. "No one once called me, but he certainly should have." The institution's Doctor had included another drug alongside my Clozaril, but Dr. Danley didn't understand why because the medication kept me from feeling perfectly normal. When it was dropped, I felt fine. We had proven over the years that a small dosage of Clozaril was all I needed.

I wonder what the pharmaceuticals push. I saw two salesmen entering that doctor's office who prescribed me sleeping pills. And, why Novartis Pharmaceuticals has received such a bad rap with Clozaril, the best anti-psychotic on the market, when the monthly CBC will reveal a low white cell count and can be stopped should that

occur. I met up with an old friend of mine recently and she revealed to me her, too, was Bipolar, then added, "I don't do anything but stay in bed all day every day." She explained she was unable to cope with life when awake. I asked her what medication she was on and she said, "Seroquel".

My son suffers from Schizophrenia. Seroquel hasn't worked for him either, so he refuses to take it. He must work and provide for a family and cannot function on the medication. Thus far, not one doctor can be convinced to prescribe Clozapine for this man. He never gets any R.E.M. sleep. One can die from that and yet they worry about a potential low CBC or other possible side-effects that can be monitored. I want my son to have a normal brain, like I now have, because "my" current doctor understands. As I said once, "There is nothing worse than losing one's mind. Death is not even worse".

I was once in the Cypress Creek Mental Facility located just outside of Houston, Texas. I made friends with a beautiful young woman who was being treated for Bipolar disorder with only Lithium. It had no effect on her. What her doctor did do was recommend electroconvulsive therapy. I was so saddened when she said, "It will only kill off two-thirds of my brain. I will have a third left." I had met her lovely husband and two small precious children. One could tell they loved their mother so. I begged her not to allow that doctor to do that to her, but to no avail. She said, "I can't go on living like this!" The doctor never tried Clozapine.

CONCLUSION

Summing things up, I have tried every anti-psychotic on the market. I must drive 15 miles monthly to get my CBC, then another 15 to pick up my meds at a pharmacy approved to carry it, but believe me it is worth every minute. Other drugs may eliminate delusions and hallucinations, but they can fail to give one a clear head and a normal thought process with the ability to focus easily.

Am I angry? Yes, I am angry. There is a wonderful drug on the market called Clozaril/Clozapine and the F.D.A. fails to understand just how effective it is and how harmless it can be for most. At 61 years of age, after taking the drug for 15 years, I am in perfect physical health. What makes me angrier, though, is seeing others who suffer from Bi-Polar Disorder or Schizophrenia and who are not doing well at all on the medications they've been prescribed. Yet they do not know there is something better out there. Then, there are those, like my son, who hate their meds so they refuse to take them. As a result, they live daily with the delusions and lack of rest due to strong, vivid nightmares throughout the entire night. I've been there and life is too tuff. I'm angry because Clozaril is not widely available at pharmacies. The F.D.A. knows all medications have potential side effects. Finally, all one must do is witness those homeless psychotic women pushing their shopping carts down the Los Angeles sidewalks to know some mental patients are being swept aside, "Because they will always be crazy." Seeing them, I don't know if I want to cry or scream. I am convinced they would not be normal again if only they could try Clozapine. I can't fight this battle alone.