User-Driven Psychiatry

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ABSTRACT

This paper begins with a personal account of the first author’s journey with a psychiatric disorder and his perception of recovery helped considerably by shared learning on the web from experiences of others with similar illnesses. This illustrates a rapidly evolving web-based model of healthcare adopted increasingly by patients worldwide to examine their own health problems along with support from health professionals, but more often with support of other people with similar illnesses. A psychiatrist’s perspective is then given.

Keywords: Bipolar Disorders, Self Medication, Thyroxine, Web-Based Healthcare, Web Support Group

A PATIENT’S PERSPECTIVE

By Siju Oommen George

INTRODUCTION

I suffered from mood swings from a very early age. I was depressed at times and then would be sometimes overjoyed suddenly with out any reason and this cycle kept on repeating itself. I had up cycles and down cycles in my emotions. During the up cycles I was very bold, jovial, had a lot of energy in my body, felt like I am on the top of the world, was arrogant and naughty and this made people to categorize me as a problem child. During the down cycles I felt guilty for no reason, depressed, lacked energy in my body, felt sleepy at all times and people attributed it to my desire for attention, sympathy etc. Though I had this difficulty I finished my schooling with fairly good marks.

When I joined College I found that I was growing tired more and more and the depression seems to last more than the jovial moods. I could not concentrate while reading, I lost my memory, and couldn’t harness my thoughts to keep them in a related chain. I was having a suspicion by now that I am mentally ill but after about 7 years it was found out that I had Hashimoto’s Disease. After I started taking medicines regularly for thyroid this problem was solved but my mood fluctuations still remained.

Meanwhile I got a job and was fulfilling my duties well. The up cycles helped me to get things done quickly and since I didn’t have to sleep during these cycles I read more and learned more and worked more. The down cycles made me stay at home but it was alright because I could do much of my work from home.

I also had other troubles like hearing voices while in a state of semi sleep and out of body experiences. In the Out of Body Experiences I

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would come out of my body and I could see my body lying down on bed. I could walk outside without my body, go in through holes out of a room and even walk up in the air. In order to get inside my body I had to come back and touch it and my body would suck me in and then after several tries I could get back up with my body.

At this point of time I met an endocrinologist who took more than 3 times the fees of other regular endocrinologist. He gave me the Idea that I could slowly reduce the amount of medicine I was taking and my thyroid glands will pick up the production of thyroxine.

I was taking levothyroxine 1 x 100 mcg (0.1 mg) oral tablet one time per day in the morning and I slowly reduced it to half and gradually quit.

This caused my mood swings to go wild and I found myself with my first psychiatrist. He tested my Thyroid and asked me to continue levothyroxine and gave me medicines for depression but it did not work well with me. So I met another psychiatrist who was supposed to be the best in town. He seemed to know it all and told me a lot of things about me some of which are not true but since he had a medical name for each of my abnormalities I thought he could help me and continued treatment with him. His first demand was that I do not research on the drugs he gives me and I was to take it by faith that these drugs will cure me. He called my mood swings “Bipolar Disorder” and my out of Body experiences “Autoscopy” He said I should not take any anti-depressants since I have Bipolar Disorder and the Anti-depressant “amitriptyline” prescribed to me by my gastroenterologist was the cause of making my mood swings go wild.

I continued treatment with him and there was no change in my condition. I was treated with

- Valproic acid 500 mg 0-0-1 to control mood elevation
- Fluvoxamine 50 mg 0-0-1 1/2 to control depression.

He also told me to carry about 5 pills of

- Risperidone 0.5 mg always in my purse so that i can take it when I feel I am about to pick up a fight and within 10 minutes it will calm me down.

Now for Autoscopy: he told me to take

- Oxcarbazepine 300 mg 1-0-0
- Clonazepam 0.25 mg 0-1-1

Also for good bowel moements:

- Levosulpiride 50 mg 0-0-1/2

He added that Bipolar Disorder was seasonal and is found to increase in intensity during certain months like March, April, May etc. and advised me to take caution. He also advised me to find somebody to warn me when I am going off limits on my mood to warn me because I may not always feel the difference.

I was seeing many dreams in which I was nude and it was really bothering me. About the nudity in dreams he said it is indicative of losing control of oneself and since I have started seeing my self wearing shirt in my later dreams it can be considered as an improvement but he said not to give too much attention to it.

He took an MRI scan of my Brain to see if there is any brain damage to explain the reason for Autoscopy but could not find any. His medicines did not do me any good other than waste a lot of money. I complained that my moods were cycling several times during a single day and he said it is just my feelings and rapid cycling will take at least 2-3 days interval to happen. He stopped the medicines for Autoscopy since he did not find any improvement and after 1 year of treating me without seeing any improvement he threw the file at me and asked me to go elsewhere accusing that I am not cooperating with the treatment. Being frustrated I resorted to smoking and taking alcohol for some comfort but I felt all the more miserable.
Virtual Communities, Machine Learning and IoT: Opportunities and Challenges in Mental Health Research
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