Stranger Than Fiction

Vicky’s OCD got so bad that her doctor called for psychosurgery. Just don’t call it a lobotomy.

This is Vicky’s brain. The circles mark dark spots where tissue was burned away.

Amber says the "doom and gloom" period started when her daughter Vicki, now 22, turned 16. "Vicky thought she was going to be raped and did 20 sets of 20 rituals, like counting and checking behind doors to prevent bad things from happening," Amber says. "She couldn't eat and sleep, it took over her whole mind." When Vicky, a straight-A student, started talking about suicide, her parents took her to a shrink near their home in Edmonton, Canada. She was diagnosed with obsessive compulsive disorder (OCD), and Amber began feeling like Vicky’s illness “was our fault” (many patients with anxiety disorders say they had overprotective and unaffectionate parents.)
Then Amber met OCD specialist Dr. Lorne Warneke, who "respected us and told us it's a physical illness." Over time, Lorne put Vicky on 17 different anti-depressants but as with nearly half the people who take these drugs, they didn't work. One reason for drug failure rates in women is that, even though women are twice as likely to have anxiety disorders, the medicines to treat them are tested primarily on men during development.

When the drugs failed Vicky, Lorne tried electroshock therapy, then suggested an anterior capsulotomy, a type of psychosurgery that doctors sometimes use to treat severe cases of OCD and anxiety. Lorne describes the surgery, which severs the pathways between the brain’s frontal lobes and the areas that control emotion, as "a bit like cutting some wires in a telephone line to reduce the amount of messages getting through."

No one’s keeping score, but a conservative estimate is that each year in the U.S. and England (where two-thirds of psychosurgery patients are women) at least 25 people get their wires cut in places like Massachusetts General Hospital, Brown University affiliate Rhode Island Hospital and San Diego’s Gamma Knife Center. UCLA, the University of Illinois at Chicago and Vanderbilt University are all considering their own psychosurgery programs. A recent poll in the Journal of Clinical Neuroscience found that 74 percent of psychiatrists would consider psychosurgery for their patients.

“They shaved tiny circles off my hair and made two holes in my skull," Vicky recalls. "I didn't feel nothing, but I was terrified. I wanted my mom. There was a lot of blood and guck."

That first surgery almost cured me, 75 percent," Vicky adds. But her OCD came back. Six months later, Lorne recommended follow up surgery, something that's done in about 45 percent of psychosurgery patients. By age 19 Vicky had had a third.

"I'm just not happy with my life," Vicky says now as her pet bird budgie Britney, named after Britney Spears, starts tweeting like crazy. Vicky says she’s had seizures and extreme fatigue and gained about 40 pounds post-op which is common, especially with women.

"I have forgetfulness and my concentration is really bad," Vicky says. "I feel like I'll never change, lose the weight, have a boyfriend, go to university. I don't feel like myself anymore. I sometimes want to die and go to heaven and relax and be calm."

"It is, of course, mad," says Dr. Susanne Bejerot of Vicky's situation. Susanne spent six months at Karolinska Institute, the Swedish medical center that developed anterior capsulotomy. She says she saw a scary range of post-op personality changes, like hypersexuality and aggressiveness, which made her wonder if these surgeries are creating "ticking bombs." In a 2002 study, the American Journal of Psychiatry found that less than
half of psychosurgery patients had improved enough to regain basic life functions, like going back to work.

"Women are more vulnerable to psychosurgery," warns psychiatrist Dr. Peter Breggin. Some researchers say that's because female brains have 15 percent more cell density than male brains in certain areas of the frontal lobes. "But everybody gets worse," Peter continues. "It always impairs higher functioning and the most sensitive aspects of the human being: having an abstract conversation, empathy, love, goals."

“It caused me more harm than good,” Vicky claims of her psychosurgeries. But Lorne maintains that "the procedure has no negative effects" and is contemplating a fourth surgery for Vicky. Her mother says that would be "great," claiming Vicky has become aggressive.

Lorne’s hoping a cingulotomy or a prefrontal leukotomy will work this time. "Why not," he asks, "if you've tried one approach and the patient's life is a shambles?" -Danielle Egan

First published in Jane Magazine, June 2004