Case #3: Bodily Identity Integrity Disorder

Since she was a young child, Jewel Shuping dreamed of being blind. “When I was young my mother would find me walking in the halls at night, when I was three or four years old,” she says. “By the time I was six I remember that thinking about being blind made me feel comfortable.” She would stare at the sun for hours, hoping that it would damage her eyes. As a teenager, she began wearing thick black glasses and carrying a white cane. By the time she was 20 years old, she was fluent in braille. Shuping describes her desire to be blind as a “non-stop alarm that was going off” in her head. Finally, at nearly 30, she found a psychologist willing to help blind her by putting a couple of drops of drain cleaner in each eye. Though the process was painful, she remained hopeful: “all I could think was ‘I am going blind, it is going to be okay.’”

The drain cleaner severely damaged her eyes but did not render her completely blind, so she is not totally satisfied with the result. However, she is happy to be “much further along her path to blindness.” She explains: “I really feel this is the way I was supposed to be born, that I should have been blind from birth. When there’s nobody around you who feels the same way, you start to think that you're crazy. But I don't think I'm crazy, I just have a disorder.”

Bodily Integrity Identity Disorder (BIID) is a rare condition where there is a conflict between a person’s actual, physical body and their idea of how their body should be—usually, an able-bodied person who believes that they should be disabled. The most common manifestation of the disorder is a desire to have a specific body part amputated. Dr. Michael First, a professor of clinical psychology, coined the term BIID. He explains:

Any major disability can be a focus of BIID, from amputation to paraplegia and blindness. These people are aware that this feeling of theirs is unusual—they know it is coming from within them. They can’t explain it. But because of this level of awareness we don’t consider this to be something that we would consider evidence of psychosis. In the world of psychiatry cures are rare, very often it’s about asking how you make someone’s life fulfilling despite their condition. Now the problem of course if you have a particular individual who wanted amputation or who wants to be blind--how do you know once you have done it that they are going to be satisfied?

And it is true that the procedure will not cure the underlying disorder. But for many people who have BIID, the desire to make their body match their identity is extremely strong—so strong that they are will to take desperate measures to make it happen.

Because it is so difficult to find a doctor to perform the surgery, however, some people with BIID resort to harming themselves. They might put drain cleaner in their eyes to blind themselves, like Jewel Shuping; they might shoot their leg off to remove the offending limb; they

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3 “Bodily Integrity Identity Disorder,” biid.org, last updated 2016.
might jump off a cliff in an effort to paralyze themselves.\textsuperscript{5} A doctor cannot amputate a healthy limb without risking his or her license. A Scottish surgeon who performed two such surgeries in the late nineties was banned from performing any more—even though he had given the issue considerable thought, consulted his professional organization, and received written permission from his hospital’s chief executive.\textsuperscript{6} And indeed, his patients were convinced that surgery was the only relief for their condition and were completely happy with the results of the procedures. One patient says he finally feels like “a complete person” now that he is an amputee.\textsuperscript{7}

Case from the 2016 Regional Ethics Bowls

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