

At War With Their Bodies, They Seek to Sever Limbs

By ROBIN MARANTZ HENIG

When the legless man drove up on his own to meet Dr. Michael First for brunch in Brooklyn, it wasn't just to show Dr. First how independent he could be despite his disability.

It was to show Dr. First that he had finally done it — had finally managed to get both his legs amputated, even though they had been perfectly healthy.

Dr. First, a professor of psychiatry at Columbia University, had gotten to know this man through his investigations of a bizarre and extremely rare psychiatric condition that he is calling body integrity identity disorder, or B.I.I.D.

"This is so completely beyond the realm of normal behavior," he said of the condition, which he estimated afflicts no more than a few thousand people worldwide. "My first thought when I heard about it was, Who would think this could go wrong? Who even thought there was a function that could be broken?"

Dr. First is among a small group of psychologists and psychiatrists who are trying to define the disorder, understand its origins and decide whether to include it in the encyclopedic bible of psychiatry, the Diagnostic and Statistical Manual, or D.S.M., as a full-fledged disease. At the same time, the disorder is turning up as a plot device or documentary subject in a handful of films, plays and television shows.

The idea of having extreme elective surgery, even when it involves mutilation or removal of healthy tissue, has met at least some acceptance in cases like sex reassignment, or cosmetic surgery for those who hate their noses or breasts even when those body parts are objectively fine.

But an obsessive desire for a limb amputation — one that drives people to cut off healthy arms and legs — tests the tolerance of even the most open-minded.

Body integrity identity disorder has led people to injure themselves with guns or chain saws in desperate efforts to force surgical amputations. A few have sought out amputations abroad, including one man who died of gangrene after an elective amputation in a clinic in Tijuana, Mexico.

The disorder has been known by several names. In 1977, Dr. John Money, an expert on sexuality at Johns Hopkins University, named it apotemnophilia (literally, love of amputation). He considered it a form of paraphilia — that is, a sexual deviation.

In 1997, Dr. Richard Bruno of Englewood Hospital in New Jersey proposed the name factitious disability disorder, which he grouped into three types: people who are sexually aroused by amputees ("devotees"), those who use wheelchairs and crutches to make it seem as if they are amputees ("pretenders") and those who want to get amputations themselves ("wannabes"). In Dr. Bruno's taxonomy, those who manage to obtain amputations continue to be known as wannabes.

In 2000, Dr. Gregg Furth, a New York child psychologist and one of Dr. Money's co-authors on his 1977 paper, published a book about the disorder, calling it amputee identity disorder. In addition to his professional interest in the subject, Dr. Furth had



Andrea Mohin/The New York Times

Dr. Michael First, one of the few psychiatrists to study body integrity identity disorder.

a personal one: from early childhood, he had wanted to have his right leg amputated above the knee.

Dr. Furth wrote the book with Dr. Robert Smith, whom he met while searching for a surgeon who would perform the elective amputation. When Dr. Furth found him in Scotland, Dr. Smith had already done two such operations, and he agreed, after consulting with two psychiatrists, to operate on Dr. Furth. But in 2000 Dr. Smith's hospital, the Falkirk Royal Infirmary in Glasgow, prohibited any further procedures of this type. Dr. Furth never received his amputation.

The newest name, body integrity identity disorder, was first used by Dr. First of Co-

Psychiatrists are struggling to define a rare disorder.

lumbia in the journal *Psychological Medicine* in 2004. In that paper, he described the results of a telephone survey of 52 people with the disorder: 9 of them had amputations and the rest yearned for it. He chose the name to distinguish the disorder from paraphilia, psychosis or body dysmorphic disorder (the false belief that a part of your body is ugly or abnormal).

To Dr. First, the closest analogy was to gender identity disorder.

"When the first sex reassignment was done in the 1950's, it generated the same kind of horror" that voluntary amputation does now, Dr. First said. "Surgeons asked themselves, 'How can I do this thing to someone that's normal?' The dilemma of the surgeon being asked to amputate a healthy limb is similar."

Still, the analogy is imperfect. "It's one

thing to say someone wants to go from male to female; they're both normal states," Dr. First said. "To want to go from a four-limbed person to an amputee feels more problematic. That idea doesn't compute to regular people."

Dr. David Spiegel of Stanford said he believed that body integrity identity disorder sounded closer to either body dysmorphic disorder or anorexia nervosa, though he added that he had not seen any patients with the integrity disorder. The connection to anorexia, he said, is that people with B.I.I.D. "have a clearly mistaken belief about their bodies."

"It reminds me a little of anorexia nervosa," Dr. Spiegel added, "where people think they're fat when it's obvious they're not."

No one knows for sure what causes the integrity disorder or how it can be treated. Dr. J. Mike Bensler and Dr. Douglas S. Paauw of the University of Washington Medical Center in Seattle, writing in the *Southern Medical Journal* in 2003, said it was probably both sexual and emotional in nature. The condition is at its heart an "erotic fantasy," they wrote, with two components: "undergoing amputation of a limb, and subsequently overachieving despite a handicap."

According to Dr. First, people with body integrity identity disorder are quite specific about how many limbs they want amputated, and where. The most common is the left leg above the knee; the least common is a finger or toe. "Some people actually know the exact spot where they want the amputation," said Dr. First. "Not just above the knee, but four inches above the knee."

Anything short of that specific site can be insufficient. One man from Dr. First's sample had a lifelong fixation on being a double leg amputee. After a shotgun accident, he lost his left arm. Amazingly, this did nothing to diminish the intensity of the man's desire to have his legs amputated.

In Dr. First's study, just over half of his subjects had encountered amputees at a young age, and from that time on, they were fixated on getting their limbs removed.

"It wasn't so much that I wanted to be an amputee as much as I just felt like I was not supposed to have my legs," said Dr. First's brunch companion in a phone interview, which he granted on the condition of anonymity. The man also was a subject in Dr. First's study.

"From the earliest days I can remember, as young as 3 or 4 years of age, I enjoyed playing around using croquet sticks as crutches," he said. "I enjoyed thinking about what it would be like to be missing a leg. When we were playing cowboys and Indians, I seemed to be the person who always got wounded in the leg."

This man said his amputations cured his disorder. But Dr. Spiegel said most such operations would probably not do away with the underlying problem. "I don't think the answer is fitting in with the obsession or delusion," he said.

Dr. Spiegel expressed more faith in psychotherapy, especially something called response prevention and thought-stopping. "It involves training the patient to try and block the thought when it comes up," he said, "and to keep him from trying to act on it."

None of the subjects in Dr. First's study reported being helped by therapy or medication, but Dr. First said that might be because they had not received "psychotherapy tailored to this disorder" or "high sustained doses" of medications used to treat related conditions like obsessive-compulsive disorder.

He said more research was needed into treatment options and into whether amputation was an acceptable treatment "as a last resort."

People who have lost limbs to accidents or disease are often horrified when they learn about healthy people who seek amputations.

"It's very difficult for people who have been through what they consider to be a devastating life experience to understand why anybody would want to mutilate himself in this way," said Paddy Rossbach, president of the Amputation Coalition of America, an advocacy and support group. "Especially when so many people are having tremendous problems with prosthetic fittings, or access to prostheses, and are living with pain every day of their lives."

Mrs. Rossbach, who has been missing a leg since childhood, said that some amputees are angry at people with body integrity identity disorder because they believe that the condition "is really minimizing what they themselves have been through."

According to Dr. First, people with the disorder are basically normal. "They have families," he said. "They hold all kinds of jobs, doctors and lawyers and professors. They're not screwed-up people apart from this. You could spend an evening with them and never have the slightest clue."

But people with serious mental illnesses, even psychoses, often look normal on the surface, Dr. Spiegel said. Still, the surface can mask some profound problems. "It's often the case that people with this kind of delusion would pass a mental status screen," he said. "They can do abstract thinking, they're not disoriented, they look pretty good to the outside world as long as you don't trip over their delusion."

Yet many with the disorder would go to

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extreme measures to get rid of the limb they consider extraneous.

In May 1998, the urge drove one man to a California surgeon who had lost his license more than 20 years earlier for several botched attempts at sex reassignment surgery. At a clinic in Tijuana, the surgeon, John Ronald Brown, 77, cut off the left leg of Philip Bondy, 79, of New York, who had paid him \$10,000. Then Mr. Brown sent Mr. Bondy to a motel in a run-down section of San Diego to recover on his own.

Two days later, Mr. Bondy was dead of gangrene, and Mr. Brown was charged with second-degree murder. During the trial, newspaper reports said that Mr. Bondy had sought the operation to satisfy a "sexual craving." Mr. Brown was found guilty in October 1999 and sentenced to 15 years to life in prison.

Mr. Bondy was not alone in his desperation. Among the body integrity identity disorder sufferers in the documentary "Whole" by Melody Gilbert, broadcast on the Sundance Channel in May 2003, is a Florida

man who shot his own leg so it would be amputated in the emergency room, and a man from Liverpool, England, who packed his leg in dry ice for the same reason. The man who froze his leg referred to the resulting amputation as "body correction surgery."

The condition is slowly making its way into popular culture. At the New York International Fringe Festival last summer, an award for best overall production went to "Armless," a play about a middle-aged suburbanite with the disorder. The playwright, Kyle Jarrow, said his goal was to explore "the line between gross and spooky and funny and poignant."

In November, an episode of "CSI: New York" featured a man with the disorder who bled to death after he tried to saw off his leg. And last month, a screening was held in the East Village of "Pretender's Dance," a short film by Tom Keefe about a young choreographer and her boyfriend who wanted amputation.

Dr. Smith, the Scottish surgeon who removed the legs of two men before his hospital forced him to stop, is trying to get the disorder formally recognized so that the amputations

can be covered by the National Health Service.

"The Hippocratic oath says first do your patients no harm," he said in the film "Whole." But maybe the real harm, he said, is to refuse to treat such a patient, "leaving him in a state of permanent mental torment," when all it would take for him "to live a satisfied and happy life" would be to amputate.

Dr. Smith's American co-author, Dr. Furth, is trying to get body integrity identity disorder added to the D.S.M., the textbook compiled by the American Psychiatric Association that lists all mental disorders considered distinct, pathological and worthy of reimbursement by health insurance companies.

Dr. First of Columbia is on the board of editors for the next edition of the textbook. Even though he is one of the few psychiatrists who studies the disorder, he still has not decided whether it should be included. Putting the disorder into the manual could generate research interest into its origin and possible treatment, he said.

But, he added, "the D.S.M. already is a very big book."

"And as far as clinical utility," Dr. First said, "the thicker it gets, the less useful it gets."

And while the disorder is genuine, he said, he has to recognize that it may be too rare for mention in a book that is already buckling under the weight of its inclusiveness.

Science Times

The New York Times

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In a rare and baffling disorder, people want to have their healthy limbs amputated.