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Amputee wannabes

Why do some people want their healthy limbs removed?

Melody Gilbert

George Boyer, holding a photo of himself, is pleased with the way he looks after his amputation.

By Carl Elliott
SLATE.COM

July 10 — Baz remembers first seeing an amputee when he was a 4-year old boy in Liverpool. By the time he was 7 he had begun to think, “This is the way I should be.” It was not until Baz was in his 50s, however, that he actually had his leg amputated. Baz froze his leg in dry ice until it was irreversibly damaged, then persuaded a surgeon to complete the job. When he awoke from the anesthetic and his left leg was gone, he says, “All my torment had disappeared.”

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WHOLE, A RIVETING new documentary by Melody Gilbert that recently premiered at the Los Angeles Film Festival and will soon be shown at festivals in Calgary and London, is about an increasingly visible group of people who call themselves "amputee wannabes." Wannabes desperately wish to have their healthy limbs removed, and some have succeeded in having it done. Kevin, a university lecturer and one of several wannabes featured in the film, had his leg amputated by Robert Smith, a surgeon in Scotland who has amputated the legs of two otherwise healthy people. George Boyer shot his own leg off with a shotgun. Others have used chain saws and homemade guillotines. Why? Nobody really knows, including the wannabes themselves, who often say they have had the desire since they were children. "It's obviously peculiar," admits Kevin. "But knowing it is peculiar and saying it is weird does not do away with the problem."

FEELING WHOLE

In the same way that some people said they only felt like themselves after, say, getting sex-reassignment surgery, or even taking Prozac, many wannabes said they would not feel like themselves without an amputation.

My interest in amputee wannabes began several years ago when I was writing my book *Better Than Well: American Medicine Meets the American Dream.* I was trying to understand why so many people have begun to use the tools of medicine for purposes other than curing illness, such as self-improvement and self-transformation. I noticed that in the same way that some people said they only felt like themselves after, say, getting sex-reassignment surgery, or even taking Prozac, many wannabes said they would not feel like themselves without an amputation. I published an article about wannabes for the *Atlantic Monthly* and another on the legality of such amputations with my colleague Josephine Johnston for the academic journal *Clinical Medicine*. It was after reading about wannabes in the *Atlantic Monthly* that Gilbert decided to make her film.

Gilbert's sensitive film allows wannabes to speak for themselves. Many are so articulate and likable that no matter how difficult you find it to understand their desire, you will come away from the film with sympathy for their strange predicament. Yet perhaps the most disturbing figures in *Whole* are the clinicians. Even as the wannabes admit how baffling they find their own desires, the mental health professionals in the film speak with absolute confidence. The film

features a social worker and clinical psychologist who have counseled Boyer in Florida, as well as Michael First, an academic psychiatrist at Columbia University, who has organized several meetings of wannabes and clinicians in New York. First says that the purpose of these meetings is to “facilitate treatment” for the condition, by which he says he means surgical treatment. His apparent certainty that nothing short of amputation can help these people is underscored by ominous music and a screen shot that reads, “There are no medications or therapies known to help wannabes.”

This "wannabe" wraps up his leg with athletic tape so he can practice being an amputee.

Melody Gilbert

This claim is not so much false as incomplete. No formal research studies on treatments for wannabes have ever been undertaken. In fact, nobody really knows much about this condition. Only a handful of articles about it have been published, most of them small case studies in obscure medical journals. You might think that clinicians would want to be certain that all options had been exhausted before recommending that patients have their arms or legs amputated, yet the clinicians in the film do not mention alternative treatments. The only person who expresses a hint of uncertainty is Robert Smith (the Scottish surgeon mentioned above); he wonders how the amputations he has performed will be perceived in 20 years.

PROBLEM OF IDENTITY?

Dissenting voices of any kind are largely absent from *Whole*. In her eagerness to document the extraordinary stories her subjects tell (and perhaps to gain their trust), Gilbert has produced a film that uncritically accepts those stories at face value. The patients explain what this condition is and how it should be treated, and the clinicians obediently nod their agreement. The only skeptical voice in the film comes from Jenny, the wife of an American wannabe living in France. When Jenny decides she cannot stay married to a man who wants to cut his own leg off, her husband accuses her of being narrow-minded.

Oddly, the film also glides past the sexual aspect of the condition and views it as a problem of identity, like gender identity disorder. (A rare exception is a moment in which Boyer points to a sketch of a boy amputee and says, obliquely, “I could even get turned on by that.”) In the few medical articles where the condition has been discussed, it is known as “apotemnophilia,” because clinicians view it as a paraphilia — a displaced sexual desire like transvestism, voyeurism, and pedophilia. This is because many wannabes are attracted to the idea of themselves as amputees, and some are attracted to other amputees.

When I first wrote about this condition in the *Atlantic*, I worried that more people might start to identify themselves as wannabes and seek out amputation. Anyone with a rudimentary familiarity with the history of psychiatry cannot help but be struck by the way that mental disorders come and go. Conditions like social anxiety disorder, post-traumatic stress disorder, attention deficit-hyperactivity disorder,

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gender identity disorder, multiple personality disorder, anorexia, and chronic fatigue syndrome were once seen as rare or nonexistent, then suddenly they ballooned in popularity. This is not simply because people decided to “come out” rather than suffer alone. It is because all mental disorders, even those with biological roots, have a social component. While these new conditions are very different from one another, they share several important features.

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First, the conditions are usually backed by a group of medical or psychological defenders whose careers or reputations depend on the existence of the disorder and who insist that the condition is real. Second, there is usually no hard data about the causes or the mechanism of the condition. Third, no independent lab tests or imaging devices are available to provide objective confirmation of the diagnosis, which is usually made solely on the basis of the narratives and behavior of their patients. Finally, there is often (but not always) a treatment for the condition even in the absence of knowledge about its causes and mechanism. The diagnosis of social anxiety disorder, for example, was driven by the development of profitable medications to treat it, such as antidepressant drugs.

COURSE OF TREATMENT

‘I want you to accept that this condition exists,and that the *only* way it can be sorted out is surgery.’
— BAZ
amputee speaking in film "Whole"

Soon the new conditions are discussed in journals and at conferences; clinicians start to diagnose the disorder more and more commonly; the conditions themselves become part of popular discourse and are discussed in support groups, therapy sessions, Internet venues, and in articles like mine and films like *Whole*. Patients begin to reinterpret their own psychological histories in light of what they hear, and their behavior changes to match what is expected of people with the condition they believe they have. Often they diagnose themselves and decide on the proper treatment. “I want you to accept that this condition exists,” Baz says emphatically in the film, “and that the *only* way it can be sorted out is surgery.”

Perhaps, but this can only be determined through careful study. What needs particular attention are the reasons why some people come to be sexually attracted to amputees or to the image of themselves as amputees. The form paraphilias take differs not merely among individuals, but from one culture and historical period to another. When Richard von Krafft-Ebing was writing about paraphilias in 19th-century Vienna, he described men who were sexually obsessed with handkerchiefs. That paraphilia has largely disappeared. Yet many others have emerged. What is it about our own time and place that has helped create an obsession with amputees?

By all indications, the number of people identifying themselves as wannabes is growing. Smith, the Scottish surgeon, has six more acceptable candidates for amputation. A popular wannabe listserv, whose membership was 1,400 two and a half years ago, has 3,670 subscribers today. A group of clinicians at Columbia University has

set up a Web site to provide information about the condition. They are redefining it as "Body Integrity Identity Disorder." In the meantime, psychiatrists are no closer to understanding the condition, and they are proposing no therapy other than amputation.

Carl Elliott teaches at the Center for Bioethics at the University of Minnesota. He is the author of "A Philosophical Disease" and "Better Than Well: American Medicine Meets the American Dream." He has written for the Atlantic Monthly and the London Review of Books, among other publications.

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