

Xenomelia: Profile of a man with intense desire to amputate a healthy limb



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This case report helps shed more light on this debilitating, often secretive condition

Xenomelia, literally meaning “foreign limb,” is a neuropsychiatric condition in which nonpsychotic individuals have an intense, persistent belief that one or more of their limbs does not belong to their body; instead they regard it as an alien appendage that should be discarded.¹ This unwavering, fixed belief resembles a delusion and is often debilitating to the point where the affected person strongly desires amputation of the unwanted limb. Traditionally, such requests often are denied by the medical community, which may cause an individual who has xenomelia to attempt risky self-amputation, or to injure the limb in a manner that makes subsequent amputation medically necessary.¹

The name for this condition has evolved over the years, depending on the emphasis given to specific characteristics. It was once called apotemnophilia, meaning “love of amputation,” when the condition was believed to be a fetish involving sexual gratification derived from being an amputee.^{2,3} The term “body integrity identity disorder” (BIID) was introduced several decades later to incorporate the condition into a broader spectrum of accepted psychiatric pathologies, reasoning that it was the cause of a mismatch between objective and subjective body schema, similar to anorexia nervosa or body dysmorphic disorder.^{4,5} This name also served to draw parallels between this condition and gender identity disorder. However, unlike these other disorders, individuals with this condition have sufficient factual insight to know they appear “normal” to others. The newest term, xenomelia, was established to acknowledge the neurologic component of

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the condition after neuroimaging studies showed structural changes to the right parietal lobe in individuals who desired amputation of their left lower limb, thus linking the part of the brain that processes sensory input from the affected limb.⁶

While particular nuances in symptomatology were modified in formulating these older names, certain hallmark features of xenomelia have remained the same.⁷ The condition starts in early childhood, prior to puberty. Those who have it feel intense distress, and are resigned to the notion that nothing but amputation can alleviate their distress. Xenomelia is overwhelmingly more common in males than females. It is accompanied by nontraditional attitudes about disability, including admiration of amputees and complete apathy and disregard toward the impairment that amputation would cause.

While the data are insufficient to draw a definitive conclusion, the trend in the published literature suggests in xenomelia, the lower left leg is predominantly the limb implicated in the condition, in right-handed individuals.¹

Here, we describe the case of a young man, Mr. H, with xenomelia who contacted us after reading about this condition in a review we recently published.¹ He agreed to allow us to anonymously describe his history and symptoms so that clinicians can recognize and help other individuals with xenomelia. His history may also help stimulate exploration of etiological factors and novel treatment strategies for xenomelia, other than amputation of a healthy limb.

CASE

'I have this limb that should not be'

Mr. H, age 31, is a white male of Eastern European descent who was born, raised, and resides in a major metropolitan area in the western United States. He is married, college-educated, and currently works as a computer programmer for a prominent technology company. During our conversation via telephone, he exhibits above-average intelligence, appears to be in euthymic mood, and speaks with broad affect. Mr. H displays no psychotic symptoms such as overt delusions, hallucinations, reality distortion, or response

to internal stimuli. His past psychiatric history includes attention-deficit/hyperactivity disorder (ADHD), which was diagnosed at age 6 and treated with appropriate medication under the care of a psychiatrist until age 18, when Mr. H decided to discontinue treatment. He no longer endorses symptoms of ADHD. He has no chronic medical conditions other than season allergies, for which he sometimes takes antihistamines, and occasional exacerbation of sciatica, for which he takes an over-the-counter nonsteroidal anti-inflammatory medication. Mr. H also has episodic insomnia, which he attributes to job-related stress and working odd hours. He was treated for meningitis as an infant, and underwent a bilateral myringotomy as a young child to treat recurrent ear infections. He has no other surgical history. He was raised in a middle-class Christian household that included both parents, who are still alive, still together, and have no significant psychiatric or medical history. He has no siblings.

Although he lives an ostensibly normal life, Mr. H suffers in silence and secrecy with xenomelia. According to him, there was never a time in his life when he didn't feel that his left leg was "too long" and he was "walking on a stilt." He says, "It takes a daily toll on my health and well-being." He can clearly recall being 4 years old and playing games in which he would pretend to injure his left leg. He says, "When we played 'make believe,' the game would always end with something 'happening' to [my left leg]." He enjoys outdoor sports like snowboarding and mountain biking, and although he denies self-injurious behavior, he says in the event of an accident, he would prefer to land on his left leg, because it is the part of his body that he considers most "expendable." One of his most vivid memories of childhood was going shopping with his parents and seeing an older man with only one leg standing on crutches in the parking lot outside the entrance. He remembers feeling "jealous" of this man.

Although his parents were not particularly wealthy, they sent him to a private Christian school for most of his childhood. Mr. H admits that while there he didn't fit in and felt like an outcast, in part because he didn't come from the level of wealth of his

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Patients with xenomelia may disregard the impairment that amputation would cause



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Neuroimaging studies have found structural changes in the right parietal lobe of patients who desire amputation

classmates, and because having ADHD left him isolative and avoidant. "I was always the one going away to take medication," he explains, and he also developed a hostile attitude. He was suspended from school multiple times for fighting. These years left him tremendously anxious and depressed, and he would often find it therapeutic to sit with his left leg bent underneath him, so as to hide its undesired portion. It was common for him to tie his leg up and stare at himself in the mirror for minutes to hours as a form of stress reduction.

Most of Mr. H's social circle is composed of friends he has known since childhood, none of whom are aware of his condition. He acknowledges that his feelings are "bizarre in nature" and so he has kept this secret on a "need-to-know" basis out of "fear of rejection, mockery, and damage to my reputation." Through the years, he has sought out and encountered others with this condition, first anonymously on the internet, then in-person once he gets to know and trust them. He claims to know and be friendly with several people with xenomelia in his own city, some of whom have undergone amputation and are extremely happy with the results. According to Mr. H, there is a community aspect to xenomelia in his city, and people with the condition often meet each other socially. He has revealed his secret to 2 women he dated, including his present wife, who he told 3 years into their relationship. "I was prepared for her to leave me," he recalls. Although he has never connected the desire for amputation with sexuality, he certainly believes that amputating his left leg would enhance his sex life. "Do I find amputees sexy?" he asks, "I would say yes." On a 10-point scale, he considers his sex life to be a "7 or 8," and it would reach 10 if he underwent amputation.

Mr. H has a calendar on which he keeps track of the days when he feels "impaired" by his xenomelia. He marks each day as either "red" or "green." So far, he does not recognize a pattern of exacerbation. "I have my good days, then I have my bad days," he laments. "On good days, I think about amputation and where my leg should actually end, but it is something I can quickly push off. On my bad days, I am constantly reminded in one way or

another that, yes, I have this limb that should not be." While he has never sought treatment for this condition from a health care professional, he developed his own therapeutic regimen that includes yoga, hiking, and daily use of cannabis, which "helps take the edge off." He used alcohol in the past as self-medication, but stopped drinking to excess when it started to disrupt other aspects of his life. According to Mr. H, the goal is to distract himself from the condition, which provides temporary relief. "I find if my mind is more engaged, the amputation thoughts are fewer and less in intensity." He reports that the months leading up to his wedding were particularly therapeutic because wedding planning provided an excellent distraction.

Overall, his current desire for amputation is steadily increasing. "Lately it has become more of a roller coaster," he says. "If there's a safe way to do it, I'll do it." An amputation would allow him to "feel good, complete, grounded, and content." If he were to undergo amputation, he would use a prosthetic in order to retain mobility and keep his physique as discreet as possible. He has made initial inquiries into getting an amputation, saying, "I have heard of rumors of surgeons willing to perform the surgery, for a price. However, I have not completed the 'vetting process' to actually come into contact with the surgeons themselves." Similar to others with xenomelia, he is easily able to draw a line on his leg, exactly where the desired amputation should occur.⁸ For most of his life, that line would have been 2 inches above his knee, but in recent years, the line has drifted lower, to 2 inches below the knee. However, he "wouldn't mind either" line of amputation. He indicates the area below the desired line is less sensitive to pain than the corresponding part of his right leg, particularly his toes.

Mr. H's wife is extremely supportive and understanding of her husband's condition, but is opposed to the possibility of amputation (**Box, page 41**).

Much left to be learned about xenomelia

What remains to be discovered about xenomelia falls into 2 areas:

- the possible usefulness of various neuroimaging modalities (morphological MRI, functional MRI, magnetic resonance spectroscopy, and diffusion tensor imaging) to identify and localize anomalous neural pathways or neuroanatomical foci associated with this condition, such as an aberrantly developed or poorly myelinated right parietal lobe, which houses the limb's physical proprioception

- a biopsychosocial inquiry into whether there exists a specific combination of a given individual's organic brain, mind, and environmental interactions that may give rise to this condition, and whether we might detect a prodrome that arises in early childhood. The objective of any research into this condition would be to minimize its effects, if not prevent them altogether.¹

As this case illustrates, xenomelia begins in early childhood, with symptoms being reported in children as young as age 3.⁷ However, no published literature has investigated these early stages. We've learned that individuals with xenomelia often can point to key childhood experiences or memories related to seeing people with amputated limbs. They remember feeling a sense of wonder, fascination, or other strong emotion. It may be in this memory that xenomelia is permanently imprinted. This was definitely true for Mr. H, who never knew a time when he didn't endure some level of debilitation from xenomelia, and distinctly remembers feeling jealous upon seeing a man with the amputated leg standing on crutches in a store parking lot. Although he has come across many amputees in his life, Mr. H says he vividly remembers everything about that particular man in that particular moment, adding "I can still see the clothes he was wearing. I can still see the cars in the parking lot." That was likely his moment of vivid and powerful imprinting.

Particularly influential changes occur in adolescence, not just in the course of physical development, but in the formulation of self-identity, which involves the inevitable comparison of one's own appearance to that of others, with heightened awareness of what others might perceive. This phenomenon is known as "the imaginary

Box

Xenomelia: A spouse's perspective

Mr. H's wife is extremely compassionate, empathetic, and supportive of her husband's struggle with xenomelia. She denies noticing any hint of his condition until he informed her. "He expected me to freak out more than I did," she recalls. In her experience, Mr. H can go days at a time without having a "flare-up" of his condition. She believes that the intermittent worsening of her husband's condition might be associated with increased work-related stress and anxiety. She encouraged him to maintain a calendar for tracking the days with exacerbations. On days when Mr. H's xenomelia is worse, she attempts to distract him with hobbies and activities. She has accompanied Mr. H when he meets others with xenomelia, although she finds these meetings quite unremarkable. "They all seem like normal people," she says. "It's usually just an average conversation." While she is committed to helping her husband cope with xenomelia, she is averse to the possibility of amputation. "I'm willing to help in any way I can, but I'm hesitant for him to amputate a healthy limb," she admits. "I'm worried about his mobility."

audience," and it is often overemphasized in the minds of individuals with xenomelia.⁷ Mr. H is a textbook example of someone acutely aware of his "audience," suffering from the embarrassment that came from being less wealthy than others at his school, and having to manage his ADHD in plain sight of his classmates, who knew that he required medication. It is no surprise that he felt like an outcast and got suspended for fighting. He would relieve anxiety by tying his leg up and staring at himself in the mirror, finding refuge in front of an audience of one that understood and sympathized with his suffering.

Among the most notorious aspects of this condition is investigation into the possibility of there being a sexual component to the desire for amputation. The notion that the desire is a fetish employed for the purpose of sexual arousal was first propagated by Penthouse magazine in the 1970s.⁹ Learning that xenomelia exists in a child long before sexual maturation—and in an older adult long after sexual drive peaks—suggests

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Xenomelia can be independent of sexuality; it often is present before sexual maturation, and persists after sexual drive peaks



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In xenomelia, the desire for amputation is separate from a desire to be disabled

Related Resources

- Hilti LM, Hänggi J, Vitacco DA, et al. The desire for healthy limb amputation: structural brain correlates and clinical features of xenomelia. *Brain*. 2013;136(pt 1):318-329.
- Brugger P, Lenggenhager B, Giummarra MJ. Xenomelia: a social neuroscience view of altered bodily self-consciousness. *Front Psychol*. 2013;4:204. doi:10.3389/fpsyg.2013.00204.

the condition is independent of sexuality. However, this aspect of xenomelia continues to be investigated. A recent study found that >70% of individuals with xenomelia are at least partially motivated by the perceived enhancement in sexual gratification.¹⁰ Individuals with this motivation are predominantly male, homosexual, come from a religious background, and are far more likely to self-amputate.¹⁰ Mr. H admitted that he is sexually attracted to amputees, and while he had no complaints about his sex life, he felt it could only reach the highest levels of gratification if he were an amputee.

It is reasonable to posit that there is a genetic mechanism that creates a cortical template of one's body, and this template connects with the limbic system, encoding a visual preference for and attraction to one's own idealized and preferred body morphology that includes an amputated limb.¹¹ Therefore, if Mr. H sees himself as an amputee, it would be reasonable for him to identify with and be attracted to other amputees. However, Mr. H is clearly not preoccupied with sexuality, and believes that heightened sexual gratification would be an ancillary bonus, and not the main objective, of amputation.

Most individuals who have participated in research studies about xenomelia tend to be older, mainly in their 60s. This is

particularly true of individuals who go through with amputation. At some point, the need for a person to invoke their autonomy, alleviate their debilitation, and fulfill their desire may supersede their aversion to physical disability and social ridicule. At this stage in his life, Mr. H can't commit to going forward with the amputation. However, he regards the likelihood of undergoing amputation to be quite high. He made initial inquiries to find a surgeon who would be willing to perform the procedure. Given that he has found people with xenomelia who have undergone amputation, he will likely will be able find a surgeon to perform the procedure. Mr. H reports that just about everyone he has ever known with xenomelia who underwent amputation is completely satisfied with their decision, even years later. He has come across only one person who regretted the amputation, and he believes that person was likely suffering from other psychiatric issues, and did not have true xenomelia.

In the mind of an individual with xenomelia, the desire for amputation is separate from a desire to be disabled. Mr. H is mindful of the assumed irrationality of removing a healthy but "alien" limb to replace it with a prosthetic limb that is equally alien. The perceived irony is not lost on him. He values his mobility, and has no desire to use crutches, a wheelchair, or any other ambulatory tool. This is consistent with most individuals with xenomelia, who are neither motivated by the desire to flaunt their amputated limb, nor by the sympathy they might receive from others by endorsing impaired mobility. They don't consider themselves disabled. On the contrary, for them, amputation is a much-desired enhancement to their health and well-being.

Bottom Line

Individuals with xenomelia have the persistent belief that one or more of their limbs does not belong to their body but is an alien appendage that should be removed. Patients with this condition may resort to self-amputation or self-mutilation that requires subsequent surgical amputation. Xenomelia may be related to anomalous brain development, with a lack of neural representation of a limb in the right parietal lobe.

Increased opportunities for research

The internet, social media, and even peer-reviewed medical journals offer ever-increasing opportunities for individuals with xenomelia, such as Mr. H, to have their story told, regardless of whether they choose to identify themselves or remain anonymous. There are no published data about the prevalence of xenomelia, but it is almost certainly rare. However, if Mr. H was able to meet multiple people with xenomelia in his own city and form a supportive community with them, then perhaps it isn't exactly as rare as one might initially assume. People with xenomelia may tend to look for each other, hoping those with the same condition might show them the greatest empathy.

From Mr. H's experience, it appears that it would be possible to locate a sufficient number of individuals with xenomelia for the purposes of conducting research, which might allow for results with acceptable statistical power. There are plenty of individual patient stories, and by documenting these stories in published literature, it is likely that patterns would emerge and causality might be determined. Such data might be bolstered by a possible strong neurologic corroboration based on what is found via neuroimaging.

Informed research into xenomelia is still in the early stages, and it is clear that there is much left to discover. It is vital that, moving forward, investigation into this condition be thorough and objective, with the goal of alleviating this secretive and debilitating neuropsychiatric condition.

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It appears that it would be possible to locate enough patients with xenomelia to conduct more thorough research