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Desire for amputation of a limb: paraphilia, psychosis, or a new type of identity disorder

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ABSTRACT

Background. The objective of this paper is to describe and conceptualize an unusual and probably rare condition: the intense longstanding desire to have an amputation.

Method. Structured interviews were conducted by telephone of 52 subjects (mean age: 48·6, range 23–77 years; 47 male, 4 female, 1 intersexed) self-identified as having had a desire to have an amputation.

Results. Seventeen per cent ($n=9$) had an arm or leg amputated with two-thirds using methods that put the subject at risk of death and one-third enlisting a surgeon to amputate their healthy limb. The most common reported reason for wanting an amputation was the subject's feeling that it would correct a mismatch between the person's anatomy and sense of his or her 'true' self (identity). None were delusional. For all but one subject age at onset was during childhood or early adolescence. For those who had psychotherapy or medication there was no change in the intensity of the desire for amputation. The six subjects who had an amputation at their desired site reported that following the amputation they felt better than they ever had and no longer had a desire for an amputation.

Conclusions. These preliminary results suggest the existence of an extremely unusual clinically distinct condition characterized by a lifelong desire to have an amputation of a particular limb. The condition is associated with serious negative consequences: amputation attempts, impairment and marked distress. Reflecting similarities between Gender Identity Disorder and this condition, the author suggests that it may be conceptualized as an unusual dysfunction in the development one's fundamental sense of anatomical (body) identity.

INTRODUCTION

Over the past 30 years, case reports have appeared in scientific journals (Money *et al.* 1977; Everaerd, 1983; Schlozman, 1998; Brenner, 1999; Tavcar *et al.* 1999; Bensler & Paauw, 2003) and in the media (Dotinga, 2000; Dyer, 2000; Elliot, 2000; Horn, 2003) describing individuals with an intense desire to have an amputation, some of whom have actually performed self-amputation of an extremity. These unusual reports raise interesting questions. What possible motivations underlie the desire to have a limb amputated? Is this condition always symptomatic of another mental disorder (e.g. in response to a command hallucination in schizophrenia) or might it represent a mental disorder in its own right? In order to begin to characterize the condition and try to understand how to classify it diagnostically, the results are reported here of systematically interviewing 52 individuals who have had a desire to become an amputee.

To give the reader an overall sense of this unusual condition, a brief case description of a study subject is presented.

CASE REPORT

Thomas is a 39-year-old teacher, married for 15 years with one daughter, who had his left leg electively

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amputated above the knee 4 years prior to the study interview. Tom has always felt that having two arms and two legs made him 'incomplete' and that the amputation has, paradoxically, finally made him 'feel complete'. Although he reports that the main reason for the amputation was to make him 'whole', he reports that there is a sexual component to his desire in that he felt more 'sexual' while imagining himself as an amputee, and that as an adolescent, he would become sexually aroused when he pretended to be an amputee. He reports that prior to amputation his left leg did not feel any different from his other limbs nor did he perceive it to be ugly or deformed. He denies that a desire for attention was a motivation for the amputation, noting that he always wears a prosthesis when he is out in public.

Tom recalled first wanting to be an amputee around the age of 8 years, the age that he started folding his leg up in order to pretend that he was an amputee. He remembers seeing several amputees as a child and being interested in them, but does not recall any one particular exposure as particularly significant. Tom's desire increased progressively over his early adult years and would intensify when he was under stress. He continued to pretend at home (around 3–4 times per week) using crutches, especially at times when he was feeling anxious or depressed, experiencing the pretending behavior as a 'safety valve'.

Tom first sought psychological treatment at age 29 years, when his frustration over not being an amputee resulted in his becoming depressed and feeling suicidal. He began weekly insight-oriented psychotherapy (which he experienced as useless) and also was prescribed trials of a variety of antidepressants, anti-OCD medications and antipsychotic medications. He reported that they did not reduce his desire in any way and only made him feel worse. Deciding (after 18 months of treatment) that the psychiatric profession had nothing to offer him, he commenced his quest to find a surgeon who would be willing to do the amputation electively. He arranged for consultations with two psychologists (one with an interest in gender identity disorder) in order to document that he had no other psychiatric conditions and that the psychologists supported the surgical option. He then presented various surgeons with the limited literature about this condition and the results of the psychological evaluations. During this time, pessimistic that he would never find a surgeon willing to perform the amputation, he tried (unsuccessfully) to crush his left leg under weights. Finally after 2 years of trying, he found a general surgeon who agreed to do the surgery. Four years after the amputation, Tom reports no regrets whatsoever about having had the surgery: 'My only regret is that I did not have it done sooner.'

Different motivations for wanting an amputation have been described. Sometimes amputation attempts can be understood as manifestations of another mental disorder, such as a severe mood or psychotic disorder. For example, amputation was reported as a method of suicide in a 37-year-old female with severe depression who amputated both hands with a power saw hoping to bleed to death (Stewart & Lowrey, 1980), and hand amputation (accompanied by self-inflicted amputation of the penis) was reported in a 22-year-old male who was responding to command auditory hallucinations and delusions of guilt over perceived sexual transgressions (Hall *et al.* 1981).

Money and colleagues (1977) described two cases of individuals who wanted to become amputees because they found the idea of being an amputee sexually arousing. They identified the condition as an unusual paraphilia for which they coined the term 'apotemnophilia' (Greek for 'amputation love'). However, as the case of Thomas illustrates, his motivation for being an amputee differed from Money's apotemnophiles. Thomas reported that his primary motivation for having an amputation was to 'feel complete' and any sexual arousal related to being an amputee was only a minor component. Furth & Smith (2000) suggest that many individuals share Tom's motivations, viewing amputation as making them 'able-bodied and more fully functioning, more whole, more complete'.

This study considers the following research questions: (1) What are the motivations for the desire to be an amputee and how often is it a manifestation of a psychotic process? (2) How often does it lead to amputation attempts? (3) What are the clinical characteristics of the condition? (4) What are its origins? (5) Given that a core motivation may be sexual, are there co-morbid paraphilias? (6) Are there also desires to become disabled in some other way? (7) Given possible parallels with gender identity disorder, is there an increased incidence of gender dysphoria? (8) Is the disturbance associated with serious co-morbid psychopathology? (9) Do subjects have a family history of desire for amputation? (10) How effective has treatment (psychotherapy, surgery or self-amputation, medication) been?

METHOD

Fifty-two subjects who reported having experienced a desire to have an amputation were recruited over a 6-month period (October 2000 to April 2001) from one of three sources: (1) websites and internet discussion groups that focused on self-amputation (e.g. 'amputee-by-choice') and/or sexual attraction to amputees or others with disabilities; (2) referrals from subjects who had participated in the study; and (3) a patient of Dr Robert Smith, a Scottish surgeon who has performed amputations (Dyer, 2000) on these kind of subjects. The referral source instructed the subject to contact the author, with or without giving their real name, to schedule an interview.

The author conducted telephone interviews after receiving verbal informed consent (waiver of written informed consent was granted by New York State Psychiatric Institute Institutional Review Board). In order to encourage more complete reporting of potentially embarrassing and stigmatizing information, all interviews were conducted anonymously. A semi-structured interview was developed for this study to facilitate consistent collection of information. The interview consisted of 126 questions, the majority being open-ended. Many questions were designed to test the author's hypotheses about the etiology and phenomenology of this condition (e.g. childhood exposure to amputees, presence of gender identity issues, differences in how the target limb is experienced). Most interviews lasted from 45 minutes to 2 hours and all subjects completed the interview. Questions about general psychopathology were adapted from the *Structured Clinical Interview for DSM-IV* (SCID; First *et al*. 1999). Specifically, the initial SCID stem questions for depression, mania, somatoform disorders, body dysmorphic disorder, panic disorder, obsessive–compulsive disorder and psychotic symptoms were asked and positive responses were probed further using unstructured clinical follow-up questions. Extensive notes were taken during the interviews, and the data coded in 139 variables. Topics covered included demographics, how the subject experienced and explained the desire to become an amputee, onset of desire, course of illness, interest in other disabilities, history of pretending to be an amputee, sexual orientation and unusual foci of attraction, gender identity issues, psychiatric and medical history, and family history.

RESULTS

Description of the subjects

A total of 65% ($n=34$) of the subjects were recruited from the internet; 33% ($n=17$) by other interview subjects and one subject by the surgeon noted above. The subjects were widely distributed geographically, with 77% ($n=40$) living in the United States, and the remaining 12 subjects drawn from Canada, UK, Germany, The Netherlands, Sweden, Belgium and Australia.

The average age was 48·6 years (S.D. = 14·5, range 23–77). Forty-seven subjects were male, four subjects were female, and one was born intersexed, raised as a male and then reassigned to female. All but two subjects were Caucasian. Ninety per cent ($n=47$) had some education beyond high school; 18 had attended or completed graduate school. Most (65%, $n=34$) were currently employed; 23% were retired ($n=12$); and 7% were currently students. Only one subject was unemployed and one subject was on disability for psychiatric reasons (chronic depression).

Sixty-one per cent ($n=32$) reported their sexual orientation as heterosexual, 31% as homosexual and 7% as bisexual. The unusually high proportion of non-heterosexuals is partly explained by the fact that nine of the subjects were referred to the study by one subject who was himself homosexual, eight of whom were also homosexual. Focusing only on the 43 subjects from the other referral sources, 72% were heterosexual, 19% were homosexual, and 9% were bisexual. The significance of this rate of homosexual orientation is unclear since the baseline rate of homosexual orientation among internet users who frequent discussion groups is unknown.

The majority (60%, $n=31$) of subjects were currently involved in an ongoing intimate relationship; 38% ($n=20$) were married, 17% ($n=9$) divorced or separated, 38% ($n=20$) were never married (half of whom were homosexual or bisexual) and 6% ($n=3$) were widowed. Of those currently in a relationship, 32% ($n=10$) kept their desire for amputation a secret from

Table 1. *Reasons provided (in open-ended narrative) for wanting amputation*

	Reported as primary reason ($n=52$)	Reported as secondary reason ($n=48$) (four subjects reported no secondary reason)
Restoring true identity as an amputee	63% ($n=33$)	10% ($n=5$)
Feeling sexually excited or aroused	15% ($n=8$)	52% ($n=25$)
The attention it draws	4% ($n=2$)	6% ($n=3$)
Body sculpting, aesthetics (interested in surgically changing fingers and toes because of superior aesthetic of the amputee look)	4% ($n=2$)	2% ($n=1$)
Feeling satisfied inside (increased sense of well-being)	2% ($n=1$)	29% ($n=14$)
To overcome adversity	2% ($n=1$)	2% ($n=1$)
Related to being sexually attracted to amputees – to know how it feels	2% ($n=1$)	2% ($n=1$)
To be 'special'	2% ($n=1$)	0
My parents and others would accept me more	2% ($n=1$)	0
Makes me feel safe (reported as sequelae of childhood sexual abuse)	2% ($n=1$)	0
'Legs look ugly'	2% ($n=1$)	0

their partners. In 39% of those in a relationship ($n=12$), the partner was both aware and supportive of their desire, whereas 29% ($n=9$) had partners who were aware but were not supportive.

Amputation and amputation attempts

The most severe manifestation of this condition is that it drives some individuals (27% of the sample, $n=14$) to have a surgical or self-inflicted amputation. Seventeen per cent ($n=9$) had a major limb amputation (i.e. arms or legs), with two-thirds ($n=6$) using methods that put the subject at risk of serious injury or death (i.e. shotgun, chainsaw, wood chipper, and dry ice). The remaining third ($n=3$) convinced a surgeon to amputate their healthy limb. An additional 10% ($n=5$) amputated one or more fingers or toes using methods such as a saw, pruning shear, and hammer and chisel. Of note, three out of these five had a desire for a major limb amputation, but instead amputated a finger to explore what having an amputation would feel like; all continued to have a desire for a major limb amputation afterwards.

Among those who had not had an amputation (73%, $n=38$), approximately a quarter ($n=9$) either made an attempt or enrolled in a program to have the amputation performed surgically by the surgeon noted above, half ($n=19$) either studied methods of amputation or contacted doctors to inquire about having an amputation, and a quarter ($n=10$) only fantasized about having an amputation.

Reasons for wanting to become an amputee

During the interview, subjects were asked why they had a desire to become an amputee. All subjects reporting more than one reason (96%, $n=50$) were asked to indicate the primary reason. Table 1 presents the reasons in categories assigned by the author. The most common primary reason reflects the subject's feeling that having the amputation would correct a mismatch between the person's anatomy and sense of his or her 'true' self (identity). Examples of this are such statements as: '[After the amputation] I would have the identity that I've always seen myself as'; 'At some moment, I saw an amputee and I understood that's that the way I should be'; 'I feel like an amputee with natural prostheses – they're my legs but I want to get rid of them – they don't fit my body image'; 'I feel myself complete without my left leg … I'm overcomplete with it'; 'Sounds paradoxical – I would feel whole without my leg'; 'I felt like I was in the wrong body; that I am only complete with both my arm and leg off on the right side'.

The idea that an amputation will in some way correct an identity problem is so bizarre that it raises questions about whether this desire is based on a delusional belief about the limb. Strictly speaking they are not, as the individuals always understood that such thoughts were abnormal and they never had a delusional explanation such as 'the devil has taken over part of my body'.

Each subject was asked whether any of six hypothesized reasons for amputation applied

Table 2. *Reasons for amputation* (*responding to close-ended question*)

	Endorsed as important reason
'Because of attention it draws'	31% ($n=16$)
'In order to be disabled and have others help me'	6% ($n=3$)
'In order to feel whole, complete, set right again'	77% ($n=40$)
'In order to feel sexually excited'	67% ($n=35$)
'In order to feel satisfied inside'	83% ($n=43$)
'Process of amputation is the main focus of desire'	2% ($n=1$)

to him or her. As shown in Table 2, the most commonly endorsed reasons included 'feeling satisfied and elated inside' (reflecting a sense of well-being that would result from amputation), 'feeling whole, complete, set right again' (reflecting the feeling of restoring true identity), and 'feeling sexually excited'. Two hypothesized motivations, that some individuals want an amputation in order to benefit from being disabled or that the process of amputation itself was the main focus (self-mutilation) were endorsed by only a handful of subjects.

In order to understand the relationship between the motivation of restoring true identity and the motivation of sexual arousal, each of which have been proposed (Money *et al.* 1977; Furth & Smith, 2000) as the core feature, their joint occurrence was characterized. As can be seen in Table 3, all but one subject had either of these as a motivation, with 42% ($n=22$) having both. Restoring identity is much more likely to be reported as primary (85% of the time when reported as a motivation) than sexual arousal, which is reported as primary only 24% of the time.

The importance of sexual arousal as a motivation for amputation is related to gender in this sample. Among the four women, only one (25%) reported being sexually aroused when she thought of herself as an amputee but she noted that this was only a secondary reason for the amputation, the primary reason being to feel complete. Among the men, 34 (72%) reported feeling sexually excited when thinking of himself as an amputee; eight of these men (24%) reported that the sexual excitement was the primary motivation.

To investigate the possibility that the likelihood of reporting sexual arousal as a motivation for amputation was related to the subject's current age (i.e. older subjects might be less likely to report arousal as a motivation because of age-related general lowering of libido), mean ages of those subjects reporting sexual arousal as a motivation was compared to those subjects who denied sexual arousal as a motivating factor. For those subjects reporting sexual arousal either as a primary or secondary motivation ($n=33$), mean age was 50·2 years (S.D. = 15·2, range 23–77 years) compared to a mean age of 45·3 years (S.D. = 13·7, range 24–66 years) for subjects reporting identity as a primary or secondary reason without any reports of sexual arousal, indicating that the reporting of sexual arousal as a motivating factor is not related to current age.

Desired location for amputation

In all but five cases, subjects wanted a specific limb amputated. (One subject with a long-standing desire to be a bilateral above-the-knee leg amputee continued to want such an amputation even after having a left above-the-elbow amputation after a shotgun accident!) Over 95% ($n=50$) wanted an amputation of a major limb (as opposed to only fingers or toes). Those desiring a leg amputation ($n=38$) far outnumbered those wanting an arm amputation ($n=7$). For those wanting an amputation of a leg, the overwhelming majority (92%) wanted an above-the-knee amputation (as opposed to below-the-knee). In contrast, for those wanting an arm amputation, 86% wanted a below-the-elbow amputation (as opposed to above-the-elbow). (A possible explanation for this preference is that below-the-elbow and above-the-knee amputations permit greater functionality than above-the-elbow and below-the-knee amputations.) For those who specified laterality ($n=44$), the majority (55%, $n=24$) wanted a left-sided amputation, 27% ($n=12$) wanted a right-sided amputation and 18% ($n=8$) wanted a bilateral amputation (legs in all cases). Of note, desired location for the amputation was related to gender: Of the four women in the study, three (75%) wanted a bilateral above-the-knee amputation. In contrast, only four of the 47 men (9%) wanted a bilateral above-the-knee amputation.

Table 3. *Co-occurrence of restoring identity and sexual arousal as motivations for desire for amputation*

	Sexual arousal as primary ($n=8$)	Sexual arousal as secondary ($n=25$)	No sexual arousal ($n=19$)
Restoring identity as primary ($n=34$)	—	40% ($n=21$)	25% ($n=13$)
Restoring identity as secondary ($n=6$)	2% ($n=1$)	—	10% ($n=5$)
No restoring identity ($n=12$)	13% ($n=7$)	8% ($n=4$)	2% ($n=1$)

In the majority of cases (77%, $n=40$), the site of the desired amputation either was fixed since it started in childhood or else after an initial period of change, become stable for years. The remaining subjects had a more variable pattern (for example being satisfied by an amputation of any limb or preferring a specific location that keeps changing over time).

Most subjects reported that their perception of the limb which they wanted to have amputated did not differ from that of their other limbs. On the other hand, 37% ($n=19$) said yes when asked if the limb 'felt different in some way'. Thirteen per cent said 'yes' when asked if the limb felt 'like it was not their own' (not a delusion because they recognized that it was in fact their own). Five per cent reported that they experienced sensations in the limb less intensely (as compared to their other limbs) and 5% reported that sensations were more intense.

Onset

Age at onset was overwhelmingly during childhood or early adolescence. The three subjects who were not able to report a specific age all indicated that onset was during 'early childhood'. For those who specified an age at onset, 65% had an onset prior to age 8 years, and virtually all (98%) had an onset by age 16 years. Of note, the one subject who had an onset at age 62 years differed from the other subjects in a number of important ways: he amputated nine toes and two fingertips for erotic arousal, has pulled out most of his teeth himself, and has tattoos over 90% of his body.

In response to a question asking the subject how the desire for amputation began, a majority (56%, $n=29$) reported that it began soon after exposure to an amputee (in two cases the exposure was to media images of an amputee). Among those whose desire began after exposure to an amputee, 59% ($n=17$) reported that they experienced intense 'fascination' or 'excitement' immediately upon seeing the amputee, 21% ($n=6$) reported feeling that the observed amputee was conferred certain advantages (e.g. popularity, attention, happiness); 17% ($n=5$) felt sexually aroused, and one subject admired the amputee because of the adversity he had overcome. Among those who recalled the specific type of amputee they were exposed to ($n=24$), two-thirds reported that the location of the amputation was concordant with their current desired location.

Among the remaining subjects whose onset was not attributed directly to amputee exposure ($n=23$), 39% could not offer any explanation (e.g. 'that's just the way I felt'); 22% ($n=5$) reported that their initial interest started with having another disability (e.g. a limp or a broken leg) that evolved into a desire for amputation, and the remaining subjects ($n=9$) offered a variety of other explanations (e.g. 'I was introduced to pretending by a neighbor [5 years older] who liked to stalk amputees'; 'my father had a prosthetics shop and I was constantly exposed to them'; 'It began after my mother started fondling my legs – I felt sexually abused').

For the overwhelming majority of subjects (92%, $n=48$), the preoccupation with becoming an amputee was first manifested by their pretending to be an amputee. Reported methods of pretending include bending a leg back and tying it up, using crutches or a wheelchair, hiding a limb in clothing so it appears to be amputated, wrapping it in bandages, and using a prosthesis or fake hooks.

Impairment

Forty-four per cent ($n=23$) reported impairment in either social functioning (e.g. avoided having relationships because it would interfere

with opportunities to pretend), occupational functioning (e.g. difficulty concentrating at doing one's job because of time spent fantasizing about being an amputee), or leisure activities (e.g. difficulty focusing when reading a book). Forty-four per cent ($n=23$) also reported being distressed about having these thoughts.

Sexual attraction

The overwhelming majority of subjects (87%, $n=45$) reported being sexually attracted to other amputees, with only 13% of these ($n=6$) exclusively attracted to amputees. Subjects often explained this attraction as an extension of their own preoccupation with being an amputee (i.e. given that they felt sexually more comfortable being an amputee, they found themselves sexually attracted to other amputees as well). Twenty-nine per cent of the sample ($n=15$) acknowledged having at least one paraphilic focus that is recognized by DSM-IV-TR: eight were sexually aroused by cross-dressing (transvestic fetishism), two by foot fetishes, two by other fetishes (nylon, leather), two by suffering or pain (masochism), and one by children (without having ever acted on it).

Interest in having another disability

Subjects were asked whether they ever had an interest in becoming disabled in one of several other ways (e.g. blindness, paraplegia). The overwhelming majority (81%, $n=42$) said no; 15% ($n=8$) reported some interest in becoming paraplegic at some point in their lives (with six of them still having that interest), and one reported wanting to have a limp when he was younger.

Gender identity

All subjects were asked if they ever had 'feelings of wishing to be the opposite sex, or having the feeling of being in the body of the wrong sex'. Ten subjects (19%) said yes; the majority of whom ($n=7$) reported some history of cross-dressing behavior (not including those who only cross-dressed as part of transvestic fetishism); six out of the ten reported thoughts of getting sex reassignment surgery and one did. The individual who had sex reassignment surgery was born intersexed (partial androgen insensitivity), was raised as a male (and is attracted to females) and had surgery to render his genitalia completely female.

Co-morbid psychopathology

Subjects were evaluated for current and past history of psychopathology and appeared to have rates for both current and past psychopathology between rates generally seen in the community and rates seen in clinical samples. At the time of the interview, most (79%, $n=41$) had no significant psychiatric symptoms (apart from their preoccupation with amputation) or drug or alcohol problems. The remaining subjects had mild symptoms such as depression and anxiety. Approximately three-quarters of the sample ($n=40$) reported having had a psychiatric condition at some time in their lives, most commonly a depressive, anxiety or somatoform disorder. No subject reported any history of mania, delusions, or hallucinations. Although half ($n=25$) reported at least rare suicidal ideation at some point in their lives (with three making an attempt), only five reported that the ideation was related to their desire to have an amputation (e.g. hopelessness about not being able to get one).

Family history of desire for amputation

No subject reported a definitive family history of desire for amputation. Of course, given the secrecy surrounding this condition, it is quite possible that a family member might have also had a desire for amputation and chose never to mention it. Consistent with this possibility, six subjects reported 'suspicious' behavior in a family member such as noticing that a parent would get excited when an amputee would walk by on the street or that a parent seemed to be preoccupied with talking about amputees.

Treatment efficacy

A majority of the subjects (65%, $n=34$) had been in psychotherapy at some time in their lives but remarkably, almost half ($n=16$) never told their therapists about their desire for amputation, fearing that the therapist would consider this evidence of severe mental illness. For none of the subjects did psychotherapy reduce the intensity of the desire for amputation. Forty per cent ($n=21$) of the subjects

had taken psychotropic medication at some point in their lives (usually for depression), with 16 out of 21 a selective serotonin re-uptake inhibitor (SSRI) or clomipramine (although most were unable to recall prescribed doses). None of these subjects reported any appreciable effect from the medication on the desire for amputation (although mood often improved).

Six subjects had a major limb amputation at their desired site and reported that following the amputation they no longer had any desire for an amputation and that they felt better than they have ever felt. ('I am absolutely ecstatic; I'm in possession of myself and my sexuality'; 'the only regret is that I did not have it earlier; since I had it done 5 years ago, I've felt the best I've ever felt'; 'it finally put me at peace … I no longer have that constant, gnawing frustration'.) One female patient who wanted both legs amputated, feeling that her legs did not feel part of her, reported some decrease in intensity of the desires which she attributed to 'doing body work … focusing on remaining connected when my legs are being touched'.

DISCUSSION

The results of this telephone interview study suggest the existence of an extremely unusual clinically distinct condition characterized by a virtually lifelong desire to have an amputation of a particular limb that is associated with serious negative consequences: amputation attempts, functional impairment, or marked distress in about three quarters of the sample. The condition also does not represent a form of Body Dysmorphic Disorder as these subjects do not perceive their target limb to appear defective in any way nor do they feel embarrassed or ashamed about its appearance. Furthermore, none of these individuals are motivated by secondary gain, as suggested by Parsons and colleagues in their report of two cases of inappropriate amputation requests (Parsons *et al.* 1981).

Despite the bizarre nature of the desire for amputation, none of the individuals evaluated as part of this study were delusional. Of note, a literature review by Schlozman (1998) reported that the 11 cases of self-inflicted upper extremity amputation described in the past 30 years were all manifestations of a psychotic disorder. Perhaps this is attributable to the fact that individuals in this study had a long-standing desire for amputation, extending back to childhood or early adolescence. In contrast, the desire for amputation expressed by the individuals in the Scholzman review was relatively acute, occurring only during the course of a psychotic episode. Such individuals would be unlikely to subscribe to an internet discussion list focused on the desire to be an amputee.

For the small group of study subjects for whom sexual arousal is the primary motivation (15%), the diagnosis of apotemnophilia is appropriate (DSM-IV-TR paraphilia not otherwise specified). However, for the majority (73%) for whom the primary goal of amputation is to match their body to their identity, no DSM-IV-TR diagnosis even remotely fits. The diagnostic category that most resembles the phenomenology of this condition is Gender Identity Disorder (GID), with which it shares several key features. In both conditions, the individual reports feeling uncomfortable with an aspect of his or her anatomical identity (gender in GID, presence of all limbs in this condition) with an internal sense of the desired identity (to be the other sex in GID, to be an amputee in this condition). Other similarities include: onset in childhood or early adolescence; successful treatment by surgery for some subjects, frequently mimicking the desired identity (cross-dressing in GID; pretending to be an amputee in this condition); and for a significant subgroup of each, paraphilic sexual arousal by a fantasy of being the desired identity [in GID fantasizing about oneself as an anatomical female (called autogynephilia; Blanchard, 1991), in this condition fantasizing about oneself as an amputee (apotemnophilia)].

Reflecting these similarities, the author suggests that this condition might best be conceptualized as an extremely unusual dysfunction in the development of one's fundamental sense of who (physically) one is, and that it tentatively be called 'Body Integrity Identity Disorder'. (An alternative term to apotemnophilia is needed since the sexual arousal component is primary in only a relatively small minority of cases.) Just as GID represents a dysfunction in the development of gender identity, this disorder can

be thought of as representing a particular dysfunction of the development of one's body identity. Supporting the hypothesis that core body identity can become disturbed is the existence of individuals who – instead of wanting an amputation – want to be a paraplegic (two individuals with this desire offered to be in the study and were interviewed but were excluded from the data analysis since they never had a desire for an amputation).

If additional research replicates and expands on this study's results, could a case be made to include this condition in future DSMs on the grounds that, although rare, it is a distinct condition associated with distress, impairment, and risk of death (i.e. due to botched amputation attempts, the condition can be fatal; Ofgang, 2001)? The main argument against its inclusion is its apparent rarity. Adding rare disorders to the DSM may compromise its clinical utility by increasing its complexity. Of interest, most of the study subjects support its addition to future DSMs, hoping that its inclusion would facilitate the development of treatments, including – for some – surgical amputation.

There are several limitations to the design of this study which render the conclusions preliminary. One such limitation is the relatively small sample size. Although the subjects had some important features in common (e.g. onset in childhood or adolescence, stability of target location), more striking was the variability among subjects in terms of desired location, reasons for wanting an amputation, and how the desire began. A larger sample size might have permitted analysis of a number of potentially interesting subgroups, such as those whose motivation is primarily sexual, those with possible neurological manifestations (given its potential resemblance to post-stroke neglect syndrome), and those with possible evidence of other body identity problems (e.g. gender identity, the desire to become paraplegic). Furthermore, the small sample size precluded analysis of factors that might predict who is at risk for attempting amputation and who might benefit from surgery. It is also not known how representative this self-selected sample is of all individuals with the disorder. For example, does the fact that the sample is almost exclusively male reflect the true gender ratio of the disorder or is it an artifact of the recruitment process (i.e. primarily via the internet).

Another important limitation stems from the fact that the interviews were conducted by telephone rather than face-to-face. Although telephone interviews were necessary for practical reasons (the rarity of the condition resulted in the subjects being widely dispersed geographically) and to maintain anonymity (which was a prerequisite for many of the subjects who had never spoken to anyone about their condition), it does raise the possibility that some subjects either under-reported or over-elaborated their symptoms. Attempts to verify information by contacting informants were precluded by the need to maintain the anonymity of the subjects. It is also possible that the subjects' own understanding of their condition may have been contaminated by exposure (via internet discussion groups) to the narratives of other subjects. Many subjects reported at first being completely baffled as to why they had a desire for amputation and each initially felt like he or she was the only person in the universe with this bizarre desire. Although the knowledge that there was a community of individuals on the internet with this desire was a tremendous relief, hearing about others' experiences may have altered their own experience of the condition.

Finally, for those subjects who reported improvement in functioning following amputation, the absence of assessment in functioning prior to amputation raises the possibility that reported improvement reflected a bias to over-report improvement to justify their having taken such drastic measures.

Although the subjects in this sample reported that neither psychotherapy nor medication appeared to be helpful in reducing their desire for amputation, future research should examine whether a psychotherapy tailored to this disorder or high sustained doses of psychotropic medication (perhaps anti-OCD medication such as a SSRI or an atypical antipsychotic medication) might be effective in relieving these individuals of their desire to have an amputation and prevent patients from taking matters into their own hands. A more provocative question is whether, as a last resort, surgery should be considered as a potential treatment for this disorder.

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DECLARATION OF INTEREST

None.

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