

Confounding Extremities: Surgery at the Medico-ethical Limits of Self-Modification

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Controversy swept the U.K. in January of 2000 over public disclosure of the fact that a Scottish surgeon named Robert Smith had amputated the limbs of two able-bodied individuals who reportedly suffered from a condition known as apotemnophilia.¹ The patients, both of whom had sought and consented to the surgery, claimed they had desperately desired for years to live as amputees and had been unable, despite considerable efforts, to reconcile themselves psychologically to living with the bodies with which they were born.² Both surgeries were successful, and both patients, who had undergone psychiatric evaluation prior to the amputations, subsequently reported having no regrets.³ In the wake of a wave of sensationalistic stories in the media, the hospital at which the surgeries had been performed, the Falkirk and District Royal Infirmary, banned any future surgeries of the kind.⁴ Outraged local politicians promptly announced their intention to pass laws banning the procedure outright.⁵ One member of Scottish Parliament declared the surgery “obscene” and asserted that “the whole thing is repugnant and legislation needs to be brought in now to outlaw this.”⁶

The parliamentarian’s reaction is understandable not just on a visceral level, but on an intellectual one as well, since the apotemnophile’s desire to be dismembered is grounded in paradoxes: wholeness is experienced as incompleteness; self is experienced as alien.⁷ But the automaticity of the politician’s response suggests, even as it implicitly denies, the need to examine the cultural dimensions of the paradox and to understand what is at stake for apotemnophiles and for society at large in the proscription of amputations performed on physically healthy individuals. Although apotemnophilia is by no means common, its effects can be

quite devastating for those who count themselves among its victims. Consider the case of Philip Bondy, an apotemnophile who died from gangrene in 1998 in a San Diego motel room within days of a “back alley” amputation in Tijuana.⁸ Bondy’s case is illustrative of both the grim determination of apotemnophiles to effectuate the amputations they desire and the serious physical harm to which this determination makes them potentially vulnerable.

Whether one thinks that elective amputation should be outlawed as butchery, as suggested by the Scottish parliamentarian, or allowed (if not necessarily embraced) as a medically legitimate operative therapy for a psychiatric condition depends a great deal on how one regards the body (for example, on how one defines such terms as “bodily harm” and “bodily integrity”), and on how one delineates the limits of an individual’s consent over the disposition of his or her body. Against the backdrop of these broader philosophical questions about identity, autonomy, and the body, this article will explore the legal and bioethical implications as well as the cultural underpinnings of apotemnophilia and its surgical treatment. After first discussing the uncertain status of apotemnophilia as a psychiatric diagnosis, the article will go on to examine elective amputation in light of both the history of cosmetic surgery and the evolution of social and medical norms concerning surgical modification of the body. Finally, it will consider the legality of elective amputation in light of laws prohibiting mayhem and in the context of the regime of self-regulation that operates within the medical profession.

COMING TO TERMS: THE DILEMMA OF DIAGNOSIS AND TREATMENT

The term “apotemnophilia” was coined in 1977 by John Money, a prominent Johns Hopkins researcher working in

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the area of transsexualism and sex-reassignment.⁹ In an article published in *The Journal of Sex Research*, Money classified apotemnophilia as a condition belonging to a category of psychosexual disorders known as paraphilias, sexual preferences and behaviors that lay beyond the limits of the social mainstream to the extent that they are commonly regarded as perversions.¹⁰ In the two case studies on which the article was based, Money and his colleagues identified a nexus between sexual desire and the desire for amputation. The patients in question fantasized persistently about experiencing sex as amputees and felt that they would be unable to experience genuine sexual fulfillment as able-bodied individuals.¹¹

Inspired by the sexual dimension of the early case histories, "apotemnophilia" remains the term by which the condition is known, but cases that have come to light over the decades since the term was introduced suggest that the etiology and symptomatology of the condition are more multidimensional than Money had thought. More recent publications on the subject downplay the element of sexual fetishism, suggesting that although it is operant in some, it is not generalizable to all apotemnophiles.¹² Researchers currently working in the area assert the need for a diagnostic classification that more accurately reflects the symptoms experienced by those whose desire for amputation is motivated not by any "deviant" desire for sexual arousal or gratification but by a desire to live in a body that conforms to their body image.¹³ Apotemnophiles and their advocates today are at pains to emphasize that apotemnophilia is a broad-based identity disorder and not one that is narrowly sexually determined. The question of sexual pleasure may be implicated, they say, but only insofar as sexual identity is a constituent of identity as a holistic psychological construct.¹⁴

A Variant of Body Dysmorphic Disorder?

News reports documenting the scandal in Scotland, including those in medical journals, consistently identified the condition as an extreme variant of Body Dysmorphic Disorder (BDD),¹⁵ defined in the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-IV) as a disorder in which the affected individual is excessively concerned or preoccupied with an imagined physical defect or a minor anomaly in appearance.¹⁶ According to the literature, preoccupations associated with BDD most commonly involve the size and shape of facial features or sexual organs, but also include fixation on perceived defects in the hair (too much or too little) and skin (blemishes).¹⁷ Individuals suffering from BDD are typically so intensely fixated on their perceived flaw that they spend inordinate amounts of time thinking about it.¹⁸ They tend to suffer from high levels of stress and shame and from social and occupational impairment.¹⁹

Psychiatric treatment for BDD includes cognitive-behavioral therapy and drug therapy, but it is also the case that BDD patients pursue and receive surgical, dermatologic, dental, and other medical treatment at a high rate.²⁰ At least one small-scale study has indicated that surgical treatments for BDD patients are ineffective, but researchers agree that larger scale, long-term studies are needed before reliable conclusions about the efficacy of surgical interventions can be drawn.²¹ The outcome of these studies will undoubtedly have implications for apotemnophiles seeking surgery to "align" their bodies with their body image.

A Distinct Diagnostic Syndrome?

The classification of apotemnophilia as a form of BDD is not uncontroversial, however. In fact, it is emphatically rejected by the authors of one recent book on the subject of apotemnophilia.

Body Dysmorphic Disorder, formerly Dysmorphophobia (DSM-IV, 1994, p. 466), is one description that some psychotherapists use to label individuals convinced of a defect in their physical appearance. **THIS IS AN INCORRECT DIAGNOSIS.** Apotemnophiles do **not** believe that they have a defect in the limb or digit, for which they desire amputation. They are persons who need to have one or more healthy limbs or digits amputated to fit the way they see themselves.²²

According to the book's authors, Gregg Furth and Robert Smith,²³ the apotemnophile's problem is not that he perceives something in his appearance that isn't really there, but that he believes something in his appearance that *is* there shouldn't be there. In other words, the apotemnophile's fixation is not on any perceived imperfection in the unwanted part, but on the perceived incongruity or "otherness" of it. Ironically, the part is experienced as detracting from rather than contributing to the integrity of the body as a whole. Apotemnophiles thus paradoxically "see themselves with an amputated limb as becoming able-bodied and more fully functioning, more whole, more complete."²⁴

Campaigning for official recognition of apotemnophilia as a discrete and "legitimate diagnostic syndrome," Furth and Smith suggest that it be incorporated into the next edition of the DSM as "Body Identity Disorder" (BID). A diagnosis of BID, as the syndrome is described by Furth and Smith, would take into account four distinct criteria associated with two primary psychological traits:

Body Identity Disorder

Diagnostic features:

There are two components of Body Identity Disorder, both of which must be present to make the diagnosis. [1] There must be evidence of a strong and persistent disability Identification, which is the desire to be, or the insistence that one is, internally, disabled (Criterion A). The disability Identification must not merely be a desire for any perceived cultural advantages of living with a disability. [2] There must also be evidence of persistent discomfort about living as an able-bodied person, or a sense of inappropriateness in that same role (Criterion B). The diagnosis is not made if the condition is better explained by another medical or psychiatric diagnosis (Criterion C). To make the diagnosis, there must be evidence of clinically significant distress or impairment in social, occupational, or other important areas of functioning (Criterion D).²⁵

This definition is modeled on the DSM's description of Gender Identity Disorder (GID or transsexualism), a condition that Furth and Smith view as closely analogous to apotemnophilia in that it, too, manifests itself as an acute and unremitting experience of body/body-image disIdentity.²⁶ In the language of the DSM, "[t]he essential feature [of GID] ... is an incongruence between anatomic sex and gender Identity."²⁷ Like apotemnophiles, transsexuals want healthy parts of their bodies surgically removed in order to correct a perceived incongruence between anatomy and Identity, between body and body image.²⁸

If Furth and Smith succeed in their effort to redirect the discourse on apotemnophilia from its historical focus on sexual predilection to a focus on disability Identification, there will likely be implications for treatment as well as diagnosis. Unlike elective amputation for apotemnophiles, of which there are exceedingly few documented cases, surgical treatment for GID (in the form of sex-reassignment surgery) is reliably accessible through specialized medical centers numbering in the dozens and operating without undue political or media scrutiny throughout the world.²⁹ If Furth and Smith prevail in their bid to incorporate apotemnophilia into the diagnostic canon as an analogue of GID, it stands to reason that they may be similarly successful in bringing surgical amputation within the pale of medically acceptable treatment options for apotemnophiles. In fact, both are committed to the position that surgery should be regarded as a viable therapeutic option for at least some individuals who suffer from apotemnophilia.³⁰

There are signs that Furth and Smith's analogy between apotemnophilia and gender Identity disorder has

gained at least some purchase within the psychiatric community. A Columbia University psychiatrist who served as an editor of the DSM-IV favors the term "amputee Identity disorder,"³¹ which, like the more general term proposed by Furth and Smith, invites the GID comparison. Other clinicians, however, are unswayed by the GID parallel. One has proposed that apotemnophilia be grouped with a collection of disorders known as Factitious Disorders, in which affected individuals fabricate symptoms in order to assume the role of patient.³² He suggests a diagnosis of "Factitious Disability Disorder" (FDD), theorizing that apotemnophiles desire amputation because they desire to be loved and attended to by others in a way that they have not been in their lives as able-bodied people.³³

Under the factitious disability model, the apotemnophile seeks amputation not as a means of expressing a psychologically "authentic" self, but as a way of artificially manipulating the behavior of others to compensate for a perceived emotional lack. Not surprisingly, surgery does not emerge as a therapeutic option under the FDD model.³⁴ Presumably this is because accepting apotemnophiles' desire for amputation would be tantamount to authorizing their delusion that they are irremediably unlovable in their able-bodied state and, conversely, that they will become spontaneously lovable (and therefore loved) if they become disabled.

Ultimately, the range of options available to apotemnophiles seeking medical treatment (psychiatric and surgical) will probably be contingent to a great extent on the emergence of a definitional consensus that has not yet been reached in the psychiatric community. It is important to recognize in this context that the mental disorders and illnesses categorized and defined in the DSM are not natural and immutable constructs; they are instead the products of a fluid and evolving disciplinary discourse that is itself shaped by a constellation of powerful social and cultural factors. The history of GID as a diagnostic category is illustrative in this regard. The term "transsexual" first appeared in the professional literature in 1923.³⁵ At that time, no distinction was made between transvestism and transsexualism — conditions that have since been recognized as distinct.³⁶ It was only in the 1940s that the term came to take on its modern denotation of the desire to live permanently in the social role of the opposite gender, accompanied by the desire to undergo surgical sex reassignment to authenticate this crossing.³⁷ And it was not until 1980 that transsexualism made its first appearance in the DSM.³⁸ Between the time of the publication of the DSM-III and that of the DSM-IV, the term "transsexualism" had been abandoned in favor of the term "Gender Identity Disorder."³⁹ The DSM is thus an always-ongoing classificatory project whose categories shift, and sometimes disappear entirely, from one edition to the next. Any one of the competing models of apotemnophilia

discussed above may find its way into the DSM-V; perhaps none of them will.

If apotemnophilia is incorporated into the DSM-V in the way that Furth and Smith suggest, surgery may gain legitimacy as a possible (if experimental) treatment, and surgeons like Smith may, over time, be able to build institutional support for what is now regarded as an exceedingly marginal position. If the condition is classified in the DSM as the FDD proponents suggest, surgery will be implicitly repudiated as a capitulation to disordered thinking — a dangerously misguided treatment that mistakes the symptom for its cause. No matter how the next edition of the DSM defines the condition, if indeed it does at all, the extreme and controversial nature of elective amputation virtually guarantees that questions concerning the best medicine for apotemnophiles will remain open, and answers, when they are ventured, will be subject to considerable dispute.

A Neurological Component?

Further complicating the development of a unified diagnostic framework for apotemnophilia is the possibility that the apotemnophile's disability Identification may in fact have a neurological basis. Clinicians challenging the appropriateness of a purely psychiatric diagnosis for apotemnophiles point out that a perceived reduplication of healthy limbs is a symptom of some neurological conditions, and that people with congenitally deficient limbs have been known to experience phantom sensations in the absent appendages.⁴⁰ These clinicians postulate that patients requesting amputation may be experiencing the reverse of the "phantom limb" phenomenon; an apotemnophile may experience a limb as "not belonging" because he or she actually lacks a fully developed sensory awareness of the limb.⁴¹ Thus, apotemnophilia may be better classified as a neuropsychological problem than as a psychiatric disorder.⁴²

Anecdotal support for this conclusion can be found in the work of the neurologist Oliver Sacks, who cites a number of cases from the medical literature, some dating as far back as the nineteenth century.⁴³ In these cases, patients experiencing their limbs as radically "other" were discovered to have had lesions or tumors in the parts of their brains controlling the awareness, or *gnosis*, of the limbs in question.⁴⁴ Describing a condition whose symptoms are remarkably consistent with those of apotemnophilia, which he actually does not discuss, Sacks writes of a "pathophysiological syndrome, associated with [brain] damage ..., which could produce specific and singular changes in body-Identity — so that a patient might find a limb unfamiliar, or be unable to ascribe or relate it to himself."⁴⁵ Such a syndrome could explain the feelings of alienation that apotemnophiles report experiencing with respect to their unwanted limb(s).

The possibility that the body/body-image incongruence experienced by apotemnophiles has a neurological cause suggests that amputation may not be the only surgical intervention with the potential for affording permanent relief to apotemnophiles. Until the possibility of a neurological cause can be fully investigated, however, apotemnophiles and the psychiatrists who treat them are faced with having to choose whether the goal of treatment should be the modification of the body (to make it conform to the apotemnophile's disabled body image) or the modification of the body image (to make it conform to the non-disabled body).

THE CULTURE OF SELF-MODIFICATION AND THE DESIRE FOR DISABILITY

Surgical modification of the body for the purpose of altering or restoring appearance has a long and itself not uncontroversial history in Western societies. Medical treatises dating from the Renaissance document skin grafting and other procedures undertaken to correct defects in appearance resulting from accident or disease.⁴⁶ The term "plastic surgery" (from the Greek word *plastikos*, which means "fit for molding") was proposed in 1798 to describe reconstructive surgical procedures.⁴⁷ "Aesthetic surgery" and "cosmetic surgery," by contrast, have come to denote non-therapeutic procedures designed solely to enhance appearance.⁴⁸

The surgery requested by apotemnophiles does not fall neatly into either category. Although cosmetic concerns are not entirely remote for apotemnophiles (insofar as every body-image Ideal has an aesthetic element), such concerns appear not to be paramount. And far from restoration of physical function to a damaged or deformed limb, which is the goal of plastic or reconstructive surgery, apotemnophiles seek the disablement of healthy, functioning limbs. It is no doubt because the physical transformation apotemnophiles desire falls so conspicuously outside the boundaries of professionally and popularly accepted varieties of surgical self-modification that elective amputation has been the subject more of scandal than of serious contemplation. The result of this sensationalism is a fixation on the perceived deviance of apotemnophiles that prevents their dilemma from being taken seriously and that obscures their significant affinities with legions of cosmetic surgery patients who routinely pursue less extreme forms of self-modification.

The ever-increasing popularity of various forms of cosmetic surgery — approximately one in 150 Americans undergoes some form of aesthetic surgery every year⁴⁹ — is a testament to the fact that in contemporary society, the body is regarded not as a physiological given to which we must reconcile ourselves, but as a malleable instrument of self-expression amenable to a wide range of medical and

surgical interventions. Although the sheer proliferation of medical and surgical procedures for modifying the body is a relatively recent development,⁵⁰ there is nothing at all new about the notion that the body's appearance is fundamentally manipulable. Traditional modes of altering the body, of imbuing it with cultural meanings signifying beauty, kinship, initiation, and hierarchy run the gamut from hair styling and hair cutting, to tattooing, body painting, piercing, scarification, and even amputation.⁵¹

At the turn of the twentieth century, many physicians believed that cosmetic surgery undermined fundamental tenets of the medical profession by violating the ethical injunction against doing harm.⁵² Cosmetic surgeons seeking professional legitimacy at that time were regarded within the medical profession as little more than charlatans.⁵³ After a century of social and cultural change, however, cosmetic surgical procedures that were once considered risky and gratuitous are now commonplace. Every day, thousands of fully functional noses, breasts, chins, penises, eyelids, ears, lips, and buttocks are surgically resized and reshaped. Body parts perceived to be too small are augmented; those which are thought to be too large are reduced in size or prominence. While the dramatic shift in attitudes toward cosmetic surgery hardly forces the conclusion that elective amputation will one day be as common as rhinoplasty is today, it does suggest that beliefs about the integrity of the body and the nature of bodily harm are culturally mediated and historically contingent. As anomalous as it may seem when viewed in a historical vacuum, elective amputation becomes less incomprehensible when it is viewed as a manifestation of the continuing social and cultural evolution of attitudes toward the body and its modification.

As a result of changed attitudes toward cosmetic surgery, patients seeking cosmetic surgical procedures today, while often regarded as vain, are seldom considered mentally ill. Yet, in their quest for happiness through surgical self-transformation, cosmetic surgery patients essentially embrace the same paradox that underlies the apotemnophile's desire for elective amputation: they seek to alter themselves (i.e. physically) precisely in order to become more authentic to themselves (i.e. as they imagine themselves to be). The cosmetic surgery patient's personal Ideal, like the apotemnophile's, is an imaginary self-construct that can become reality only through surgical intervention. Cosmetic surgery patients aspire to beauty as an end in itself; apotemnophiles aspire analogously to disability. In the end, both demand surgical procedures that will align their imaginary with their real selves.

Labeling the transformation sought by apotemnophiles "self-mutilation" rather than "self-modification" or "self-transformation" — terms that typically attach to more conventional body-altering surgeries — begs the question; it presupposes that the apotemnophile's passage into

disability involves an unjustifiable assault on bodily integrity, eliding the possibility that it could be regarded more neutrally (though also much more controversially) as involving the surgically-enabled fulfillment of an alternate body Ideal. This is not to suggest that there is no meaningful distinction to be drawn between procedures like rhinoplasty and elective amputation; rather, it is to observe that what counts as "self-mutilation," or conversely as "bodily integrity," is neither universally self-evident nor historically unchanging. For this reason, the transparency of such terms cannot be taken for granted if the conversation about apotemnophilia is to be truly interdisciplinary in nature — as it must be, given that apotemnophilia is a phenomenon that involves multiple discourses, including psychiatry, cosmetic and reconstructive surgery, cultural studies of the body (e.g. disability theory), bioethics, and law.

THE REGULATION OF BODILY INTEGRITY

Assessing whether the goal of treatment for the apotemnophile should be to align the apotemnophile's body image with his or her able body or to modify the body to conform to the disabled body image implicates questions about the integrity of the disabled body and the extent to which bodily integrity and able-bodiedness should be viewed as synonymous. The debate over the social and medical status of the disabled body is one that has divided bioethicists and disability theorists alike.⁵⁴ At the heart of this debate are what Tom Koch describes as two competing models of disability: a "medical model," which emphasizes the physical limitations inherent in disability and takes for its norm the self-sufficient, non-disabled body; and a "social difference model," which defines disability primarily as a social condition resulting from society's failure to accommodate the physical differences of the disabled.⁵⁵ Proponents of the social difference model are critical of the normative thinking that stigmatizes the disabled body as a deviation from a putatively whole, fully functional body. Whereas proponents of the medical model view the disabled body as fundamentally harmed or damaged, proponents of the social difference model believe that social prejudice is the primary source of the harm suffered by the disabled.⁵⁶

Indeed, they argue, this prejudice inheres in the medical model itself, which reinforces the social privilege of the "normal" body by declining to see the disabled body as integral in its own right.⁵⁷ Under the medical model, disability is regarded as a state of physical limitation in which no rational person would choose to exist.⁵⁸ Presupposing that the non-disabled body is the object of universal desire and identification, adherents to the medical model must dismiss as necessarily irrational the apotemnophile's expression of a preference to be disabled. Situated in the context of the medical model of disability, bioethicist Arthur

Caplan's categorical pronouncement that elective amputation for apotemnophiles is "nuts," "absolute, utter lunacy"⁵⁹ seems self-evident. Stepping outside the medical model, however, the presumed mental incompetence of apotemnophiles is perhaps less obvious. Viewed from the vantage of the social-difference theorists, the apotemnophile can be understood as implicitly challenging the pervasive stigma of disability⁶⁰ not only by embracing but by seeking to literally embody an alternative conception of bodily integrity.

The value of bodily integrity is central not only to medical ethics but to the philosophical tradition upon which British and American notions of personal liberty are founded.⁶¹ By rejecting the settled equation between bodily integrity and complete able-bodiedness, apotemnophiles and the surgeons who would treat them provoke a conflict between medical authority and individual autonomy. Is it a conflict that bioethicists like Caplan can or should be empowered to adjudicate with finality? Who should decide whether a patient's right to autonomy includes the right to choose disability? Should a surgeon in whose professional judgment amputation would therapeutically benefit his patient be allowed to perform the procedure? Who, finally, has the authority to define and police the bodily integrity of the apotemnophile?

The State's Interest

Caplan characterizes on-demand surgical amputation as maiming,⁶² a term with a rich legal history that sheds light on the state's longstanding investment in protecting the bodily integrity of its citizens. Under the rubric of "mayhem,"⁶³ which Blackstone defined as "violently depriving another of the use of such of his members as may render him the less able in fighting, either to defend himself, or to annoy his adversary,"⁶⁴ acting to debilitate the body of another has been considered a crime since the earliest days of English common law.⁶⁵ The criminality of maiming another was originally predicated on the King's right to the military services of his subjects, whose bodies were always at the sovereign's disposal.⁶⁶ Any subject convicted of depriving the king of an able-bodied potential conscript through the dismemberment or permanent disfigurement of that individual answered, ironically enough, with his own limb.⁶⁷

At one time, mayhem was a separate crime under the criminal laws of almost every U.S. state; however, only a few modern criminal codes retain mayhem as a distinct crime.⁶⁸ One important element shared by all of the modern statutes is their elimination of any reference to the military origins of the crime.⁶⁹ The modern rationale for the prohibition therefore lies not in the sovereign's right to conscriptable fighting bodies, but in the state's interest in "the preservation of the natural completeness and normal appearance of the human face and body."⁷⁰

It is important to emphasize, however, that through-

out mayhem's life as a legal concept, an exception has been made for medical procedures, including the surgical amputation of limbs.⁷¹ This exception is consistent with the law's general tendency to leave judgments about necessary and appropriate medical therapies to medical professionals.⁷² Such deference is illustrated with respect to the application of mayhem laws in *Jessin v. County of Shasta*.⁷³ In *Jessin*, the defendants, physician employees of Shasta General Hospital, argued that performing voluntary non-therapeutic sterilizations on indigent patients would expose them to criminal liability for mayhem under the California Penal Code.⁷⁴ Upholding the judgment of the trial court that no criminal liability for mayhem would lie in cases involving voluntary non-therapeutic surgical sterilizations, the California Court of Appeals found that a physician performing a voluntary vasectomy would lack the malice requisite for mayhem.⁷⁵ The court's holding in *Jessin* allows that a physician may, in some circumstances, injure a patient, in the sense of disabling a particular bodily function (e.g. reproductivity), at the patient's request without incurring criminal liability.

While *Jessin's* holding extends only to non-therapeutic vasectomy procedures, it is consistent with the broader principle that surgical alterations of the body, whether therapeutic or not, fall outside the scope of the bodily harm that criminal mayhem statutes are intended to prevent. After all, when it comes to protecting the "natural completeness" of the human body, the professional obligations of physicians would seem to coincide perfectly with the state's interests. This assumed commonality of interests, reflected in the *Jessin* court's conclusion that physicians as a matter of professional calling lack malice in their treatment of patients, underlies the state's delegation to the medical profession of regulatory authority over clinical decisions and practices impacting individuals' bodily integrity.

The Medical Profession's Interests

While Caplan's charge of maiming does not raise the specter of any criminal prohibition, it does raise important questions about whether and, if so, how the medical professional establishment, in the interest of protecting itself and patients alike, should regulate the provision of elective amputation for apotemnophiles. The issue is made particularly difficult by the conceptual chasm between people like Robert Smith, who in their best clinical judgment believe that elective amputation can be therapeutically beneficial, and people like Caplan, who express an automatic but principled conviction that the surgery has no therapeutic value and represents a *per se* violation of medical ethics.⁷⁶

The difference of opinion is undoubtedly traceable, at least in part, to the competing models of disability discussed above and to the differing definitions of bodily

integrity implied in the two models. Underlying Caplan's assertion that elective amputation is a violation of the Hippocratic oath is the assumption that bodily integrity is synonymous with able-bodiedness — that any physician who disables an able body unethically inflicts harm. And underlying his assertion that the procedure is “nuts” is the belief that no person mentally capable of giving the informed consent required for surgery would consent to become disabled.

Smith, who stresses the fact that he considers patients as candidates for surgery only after they have been seen by at least two psychiatrists who confirm that they are sane and body dysmorphic, takes a different view of both the ethics of the procedure and the capacity of patients to consent to it. The psychiatrists with whom he works, he says, “have indicated that these patients perfectly understand ... the consequences of what they're requesting.”⁷⁷ In Smith's opinion, apotemnophiles are “probably the best informed patients [he has] ever had to deal with.”⁷⁸ Smith denies neither the radical nature of the surgery nor the extent to which amputating healthy limbs goes against the grain of his surgical training, but he accepts the proposition that his patients understand bodily integrity to mean something other than having “the normal complement of four limbs.”⁷⁹ The desire to have a body that is less than whole by medical standards is not for Smith, as it is for Caplan, an unequivocal sign of mental incompetence.⁸⁰

Even if apotemnophiles are regarded as competent to consent to elective amputation, however, the question remains whether the medical profession will accept (and hospital administrators permit) so unorthodox a therapy. This is a doubtful proposition for reasons that involve not only the medical profession's commitment to patient health but its desire to protect its own regulatory autonomy. *Jessin's* presumption that physicians are actuated by benign motives in their treatment of patients is consistent with the hands-off approach that the courts and the law generally take in regulating medical practice.⁸¹ To a significant degree, “courts rely on professional norms to discern what constitutes juridically acceptable professional conduct.”⁸² Thus, in creating professional norms, the medical profession to a great extent autonomously defines the legal standards to which its members will be held. This practice of independent standard-setting has been referred to alternatively as the creation of “autonomous law”⁸³ or “soft law.”⁸⁴ In essence, autonomous lawmaking is the means by which the medical profession, with leave from the state, regulates itself.

The government's traditional deference to medicine's autonomous lawmaking is by no means guaranteed, however; the possibility of active legal intervention always exists should legislators or judges perceive that the medical profession and medical institutions are not policing themselves effectively. Take, for example, the court's conclusion in *Canterbury v. Spence*⁸⁵ that “respect for the patient's

right of self-determination on particular therapy demands a standard set by the law for physicians rather than one which physicians may or may not impose upon themselves.”⁸⁶ *Canterbury* teaches that where autonomously defined professional guidelines or customs fail to adequately protect patients' health or their rights, those guidelines or customs will be subject to judicial abrogation or redefinition.

In light of the omnipresent prospect of increased legal intervention in medical standard-setting, the Falkirk Infirmary's ban on elective amputations can be interpreted in part as a defensive maneuver — as a bid to deflect unwanted media attention and to safeguard institutional autonomy in medical decision-making.⁸⁷ By demonstrating its capacity to rein in a maverick surgeon, the hospital strategically reassured the public and policy-makers that it possesses the institutional resolve to police itself and to enforce accepted professional practice standards.⁸⁸ Preempted by this exercise of autonomous professional regulation, Scottish lawmakers were effectively left with no “obscenity” to legislate against.⁸⁹

The ban at the Falkirk Infirmary demonstrates how the medical establishment, in regulating itself, becomes the de facto regulator of apotemnophiles' bodily integrity. By denying a licensed surgeon the facilities and authorization required to perform the procedure, hospital administrators exercised their professional discretion and, in doing so, declared elective amputation beyond the pale of standard care. Under medicine's regime of autonomous lawmaking (and law enforcement), both the autonomy of the patient and the professional judgment of the surgeon are ultimately subject to binding institutional judgments about the appropriateness of treatment.

Questioning the “Regulatory Ethics Paradigm”

Administrators at the Falkirk Infirmary, though quick to ban elective amputations at their facility, suggested an alternative venue. The surgery, they ventured, should be performed at a university research hospital if it is to be performed at all.⁹⁰ Implicit in this proposition are two assumptions: (1) that there is a strict dichotomy between standard and experimental care; and (2) that a regional hospital is no place for the latter. These assumptions derive directly from what George Agich calls the “regulatory ethics paradigm” (REP),⁹¹ a regime in which “innovative treatments are regarded as questionable until they are framed in a research protocol with formal mechanisms of informed consent.”⁹² According to Agich, the REP — the dominant model for managing medical innovation — has become so well entrenched that it is hardly, if ever, questioned.⁹³ Under the REP, any treatment that deviates from standard care or involves a degree of experimentation is subject to review and approval by an Institutional Review Board (IRB) and to rigorous scientific validation.⁹⁴

Despite its laudable goal of protecting human subjects of medical research, Agich suggests that the REP has come to function counterproductively by stifling innovation in clinical practice.⁹⁵ In effect, Agich argues, the REP creates the misguided presumption that without review by an IRB, and without scientific validation, innovation in medicine cannot be conducted in an ethically defensible fashion.⁹⁶ Under the REP, physicians like Smith who have not adduced formal scientific validation for the innovative procedures they perform are considered ipso facto to be operating outside the bounds of medical ethics. It is interesting to note in this regard that Smith sought and had initially received permission from the Infirmary to perform amputations on apotemnophiles, but that the hospital subsequently withdrew its authorization based on an adverse recommendation by its ethics committee.⁹⁷ In the end, the Infirmary adopted as policy what the structure of the REP mandates: amputation as a treatment for apotemnophilia must be researched scientifically before it can be offered in a routine clinical setting.

Arguing that medical ethicists need to take a broader view of the ethics of clinical innovation, Agich cites recent revisions in the *Declaration of Helsinki*, which now recognizes that in the treatment of a patient, where proven prophylactic, diagnostic, and therapeutic methods do not exist or have been ineffective, the physician, with informed consent from the patient, must be free to use unproven or new measures if in the physician's judgment they offer hope of saving life, re-establishing health or alleviating suffering.⁹⁸ This provision creates what in Agich's view is a needed exception to the stringent formal requirements associated with clinical trials and research protocols.⁹⁹ Under the terms of such an exception, Smith's provision of elective amputations to apotemnophiles could be ethically permissible even though it has not yet been experimentally investigated or validated.

It is doubtful that a university research hospital constrained by the canons of the REP would be any more receptive than the Falkirk Infirmary was to Smith's unorthodox approach to treating apotemnophilia. Some physicians, including Smith, have publicly asserted the need for formal investigation of the possible neurological underpinnings of apotemnophilia.¹⁰⁰ Their efforts may ultimately result in the kind of experimental validation required by the REP. Absent this validation, some argue, physicians like Smith who operate "outside a framework of oversight" by an IRB "set a worrying precedent" by "[blurring] an already fuzzy line between innovative therapy and clinical research."¹⁰¹ Curtis Margo argues that such "informal research" lacks a pre-specified hypothesis and is therefore prone to bias.¹⁰² In addition, he cautions, valid conclusions

concerning the effectiveness of new therapies can seldom be drawn from studies lacking adequate controls.¹⁰³

Until formal research programs can be undertaken, however, apotemnophiles are left to their own devices and to a growing body of "self-help" literature on the Internet.¹⁰⁴ There is, according to Smith, a high probability that some will "treat" themselves by staging accidents or by otherwise severing their own limbs.¹⁰⁵ One recent case of self-help amputation involved a man who severed his penis following directions and using instruments that he had acquired on the Internet.¹⁰⁶ It is also possible, as the case of Philip Bondy illustrates, that the more desperate among them will turn in their frustration to unlicensed, unscrupulous practitioners who, for a price, are willing to perform the procedure in clinical settings where regulation is sufficiently lax.¹⁰⁷

CONCLUSION

Beyond the sensationalism surrounding apotemnophilia and elective amputation lie difficult questions about the limits of both patient autonomy and professional autonomy for individual physicians whose judgment conflicts with prevailing practice standards. At the heart of these questions are deep-seated and contradictory social beliefs concerning the malleability and the integrity of the human body. On one hand, the public in the United States and United Kingdom has embraced a culture of self-modification that drives consumer demand for increasingly radical forms of cosmetic surgery. On the other hand, the public recoils at the thought of elective amputation, because as much as people have come to find it acceptable to alter the body's appearance surgically, they disbelieve that it is acceptable for able-bodied people to want to become disabled. To the extent that society and its institutions remain committed to a norm of bodily integrity that excludes the disabled body, it will remain very difficult to collectively imagine that elective amputation could be good medicine for apotemnophiles.

The debate over apotemnophilia and its proper treatment represents an opportunity that should not be overlooked to examine assumptions within the medical and bioethics communities about the meaning of bodily integrity, the limits of patient and physician autonomy, the regulatory process of medical standard-setting, and the status of the REP as the gatekeeper to innovation in clinical practice. Whether the outcome of such a debate is to reaffirm the validity of current practices and attitudes or to undertake their revision, apotemnophiles and the public in general will be best served if bioethicists and medical researchers thoughtfully — and soon — engage the confounding extremities of apotemnophilia.

REFERENCES

1. C. Dyer, "Surgeon Amputated Healthy Legs," *British Medical Journal* 320 (2000): 332.
2. *Id.*
3. S. Ramsay, "Controversy Over UK Surgeon Who Amputated Healthy Limbs," *The Lancet* 355 (2000): 476. See also Dyer, *supra* note 1, at 332 (stating that patients were "assessed and counseled by psychiatrists and a psychologist beforehand" and quoting surgeon as saying "[the patients] were delighted with their new limbs").
4. Ramsay, *supra* note 3, at 476.
5. R. Dotinga, "Out on a Limb," Salon.com, at <http://dir.salon.com/health/feature/2000/08/29/amputation/index.html?slid=974674> (last visited January 27, 2004).
6. *Id.* The politician in question, Dennis Canavan, represents Falkirk, the region in which the hospital that allowed the amputations is located.
7. The paradoxical logic of apotemnophilia is exemplified in the incongruous statements that apotemnophiles make to describe their unwanted limbs. See, e.g., Dotinga *supra* note 5 (quoting one man as saying, "It's about becoming whole, not becoming disabled."); C. Elliott, "A New Way to Be Mad," *The Atlantic Monthly* 286, no. 6 (2000): 76 (quoting a woman as saying that she "will never feel truly whole with legs" and an amputee as saying that "[his] left foot was not part of [him]"); *Complete Obsession* (BBC documentary, Feb. 17, 2000) (interviewing the same woman quoted above, who says that "at best [her] legs seem extraneous ... as if they're not a part of [her]").
8. See *People v. Brown*, 91 Cal. App. 4th 256 (2001) (upholding unlicensed surgeon's conviction on counts of second degree murder and unlawful practice of medicine).
9. G.M. Furth and R. Smith, *Apotemnophilia: Information, Answers, Questions, and Recommendations About Self-demand Amputation* (Bloomington, IN: 1stBooks Library, 2000): at iii n.1; Elliot, *supra* note 7.
10. Elliot, *supra* note 7.
11. *Id.*
12. Furth and Smith, *supra* note 9, at 13.
13. *Id.* at iii n.1.
14. *Id.* at 13. See also Dotinga, *supra* note 5 (quoting Gregg Furth, who insists that "[i]t's not about sex, it's not about getting off with someone"); Elliot, *supra* note 7 (reporting that Furth contested the premise of the question when asked whether his desire for amputation was "a matter of sex or a matter of Identity").
15. See, e.g., Dyer, *supra* note 1, at 332; Ramsay, *supra* note 3, at 476.
16. *American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders*, 4th ed. (Washington, D.C.: American Psychiatric Association, 1994): at 466.
17. A. Tasman, J. Kay, and J. Lieberman, eds., *Psychiatry* (Philadelphia: Saunders, 1997): at 1148 (1st ed. 1997).
18. K.A. Phillips and R.D. Crino, "Body Dysmorphic Disorder," *Current Opinion in Psychiatry* 14, no. 2 (2001): 113.
19. American Psychiatric Association, *supra* note 16, at 466.
20. *Id.*
21. H. Ashraf, "Surgery Offers Little Help for Patients with Body Dysmorphic Disorder," *The Lancet* 355 (2000): 2055 (reporting results of retrospective study of twenty-five BDD patients conducted by researchers at the Royal Free and University College of Medical School, London, UK, finding that BDD patients surveyed after surgery were still "significantly handicapped" by newfound complaints about their appearance). However, researchers have emphasized the need for prospective studies, see *Id.* (quoting a Stanford psychiatrist who said that "a prospective, and controlled study with long-term follow-up of BDD subjects contemplating surgery is a good idea") and Phillips and Crino, *supra* note 18, at 113 (asserting that prospective studies assessing the efficacy of surgery for BDD patients are needed).
22. Furth and Smith, *supra* note 9, at 5.
23. Furth, a practicing psychotherapist, is himself an apotemnophile seeking surgical amputation. Smith is the Scottish surgeon who performed the amputations discussed in the opening paragraph of this article.
24. Furth and Smith, *supra* note 9, at 5.
25. *Id.* at 87-88.
26. *Id.* at 89.
27. American Psychiatric Association, *supra* note 16, at 532-533.
28. Elliott, *supra* note 7, at 5.
29. See generally K. Midence and I. Hargreaves, "Psychosocial Adjustment in Male-to-Female Transsexuals: An Overview of the Research Evidence," *Journal of Psychology* 121, no. 6 (1997): 602 (setting number of centers in the Western hemisphere administering hormone and surgical treatment to transsexuals at forty).
30. *Complete Obsession*, *supra* note 7.
31. Elliott, *supra* note 7, at 5.
32. American Psychiatric Association, *supra* note 16, at 471.
33. R.L. Bruno, "Devotees, Pretenders, and Wannabes: Two Cases of Factitious Disability Disorder," *Journal of Sexuality and Disability* 15 (1997): 257.
34. *Id.* Bruno identifies behavioral therapy and psychotherapy as viable therapeutic options. *Id.* at 258.
35. P.T. Cohen-Kettenis and L.J.G. Gooren, "Transsexualism: A Review of Etiology, Diagnosis and Treatment," *Journal of Psychosomatic Research* 46 (1999): at 316.
36. *Id.*
37. *Id.*
38. *Id.*
39. *Id.*
40. K. Fisher and R. Smith, "More Work Is Needed to Explain Why Patients Ask for Amputation of Healthy Limbs," *British Medical Journal* 320 (2000): at 1147.
41. *Id.*
42. *Id.*
43. O. Sacks, *A Leg To Stand On* (New York: Summit Books, 1984): at 79-82.
44. *Id.* at 80.
45. *Id.*
46. S. Gilman, *Making the Body Beautiful: A Cultural History of Aesthetic Surgery* (Princeton: Princeton University Press, 1999): at 10.
47. *Id.* at 12.
48. *Id.*
49. *Id.* at 6 (putting the total number of cosmetic surgery procedures in the United States in 1996 at 1.9 million, up from 1.3 million in 1994).
50. Gilman, in a list presented as illustrative but not exhaustive, identifies twenty-four kinds of commonly performed cosmetic surgery procedures. *Id.* at 6-7.
51. See generally A.R. Favazza and B. Favazza, *Bodies Under Siege: Self-Mutilation in Culture and Psychiatry* (Baltimore: Johns Hopkins University Press, 1987) (discussing myriad forms of body modification, all of which the authors categorize as "self-mutilation," including ritual finger amputation among West African

Xhosa, Hottentots, Dugum Dani tribe of New Guinea, and North American Indians); J. Myers, "Nonmainstream Body Modification: Genital Piercing, Branding, Burning and Cutting," *Journal of Contemporary Ethnography* 21 (1991): 267 (reporting and analyzing results of a two-year ethnographic study of body modification in various West Coast cities, predominantly San Francisco).

52. E. Haiken, *Venus Envy: A History of Cosmetic Surgery* (Baltimore: Johns Hopkins University Press, 1997): at 1.

53. *Id.*

54. T. Koch, "Disability and Difference: Balancing Social and Physical Constructions," *Journal of Medical Ethics* 27 (2001): 370.

55. *Id.*

56. *Id.*

57. *Id.* at 371.

58. *Id.* at 372. Koch quotes one commentator who asserts that because disability is "inherently harmful," the disabled individual "has a strong rational preference not to be in such a condition." *Id.*

59. Dotinga, *supra* note 5.

60. Koch, *supra* note 54, at 370. "To use the language of Goffman, proponents of a clinical model ... are perceived by their critics as focusing on the 'stigmata,' the appearance of physical difference, one presumed to be unaesthetic and undesirable." *Id.*

61. See generally H. Teff, *Reasonable Care: Legal Perspectives on the Doctor-Patient Relationship* (Oxford: Clarendon Press, 1994). Exploring the evolution of patients' rights doctrine in common-law legal systems, Teff cites Justice Cardozo's formulation in *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125, 128 (1914), that "every human being of adult years and sound mind has a right to determine what shall be done with his own body." Teff, at 131. Teff points out that Cardozo's formulation had been anticipated in earlier decisions containing strong dicta about the individual's right to bodily integrity. Among these cases is *Pratt v. Davis*, 118 Ill. App. 161, 166 (1905), which declared that "the free citizen's first and greatest right, which underlies all the others — the right to the inviolability of his person, in other words, his right to himself." Teff, at 132.

62. Dotinga, *supra* note 5. Caplan uses the term "maiming" in its conventional sense, and not as a legal term of art. But examining the legal meaning of "maiming" is one way of beginning to understand how the state might characterize its interest in preserving the bodily integrity of apotemnophiles.

63. See *State v. Johnson*, 58 Ohio 417, 423 (1898) (stating that "[t]here is no question ... but that 'maim' as a noun, and 'mayhem' are equivalent words, or that 'maim' is but a newer form of the word 'mayhem').

64. *Id.*

65. W.R. LaFave and A.W. Scott, *Criminal Law* (St. Paul, MN: West Publishing Co., 1986): at § 7.17(a) (describing relevant English statutes enacted in 1403, 1545, and 1670).

66. *Id.*

67. *Id.*

68. *Id.*, at § 7.17(b). Some other states define crimes such as aggravated battery and aggravated assault in similar terms. *Id.*

69. *Id.*

70. *Id.*

71. *Id.*, at § 7.17(e), n.27. See also E.R. Milhizer, "Maiming as a Criminal Offense under Military Law," *Army Law* (May 1991): 8. A notable exception is *State v. Bass*, 255 N.C. 42, 52 (1961) (upholding the conviction of a physician who was found to have acted as an accessory to the felony maiming of man who cut off his fingers to collect insurance money). In *State v. Bass*, there was no claim of any therapeutic basis, psychological or

physiological, for the amputation in question; the defendant physician's motive was purely fraudulent.

72. See A. Campbell and K. Cranley Glass, "The Legal Status of Clinical and Ethics Policies, Codes, and Guidelines in Medical Practice and Research," *McGill Law Journal* 46 (2001): 476. Campbell and Glass point out that although the state is the central regulatory authority for professional groups such as physicians, a key characteristic of such groups has been and continues to be their power to control professional conduct privately. *Id.*

73. 274 Cal. App. 2d 737, 748 (1969) (holding that voluntary non-therapeutic surgical sterilization is legal in California).

74. *Id.* at 745.

75. *Id.* at 747.

76. Dotinga, *supra* note 5.

77. Complete Obsession, *supra* note 7.

78. *Id.*

79. *Id.*

80. Caplan questions the competence of apotemnophiles, whom he characterizes as "running around saying 'Chop my leg off.'" Dotinga, *supra* note 5. The issue of competence to consent is a crucial one, given the importance of informed consent to both the practice of medicine and the law of medical malpractice. It is with respect to this issue that Smith and Furth's campaign to have apotemnophilia formally recognized as a psychiatric disorder could actually present an obstacle to elective amputation. The argument that apotemnophiles suffer from a debilitating mental disorder is difficult to square with Smith's contention that apotemnophiles are fully mentally competent to consent to the amputations they seek. It is a well-settled rule, however, that the law regards patients as presumptively sane and competent to consent. R. H. Lockwood, Annotation, Mental Competency of Patient to Consent to Surgical Operation or Medical Treatment, 25 A.L.R. 3d 1439 (2001). This presumption has been held to be unaffected by the sole fact that the patient is being treated for a mental condition. *Id.* Even patients whose mental illness is sufficiently severe to justify involuntary commitment are presumed competent to elect or to decline treatment unless there has been a judicial determination of incompetency. *Mills v. Rogers*, 57 U.S. 291 (1982); *Rivers v. Katz*, 495 N.E.2d 337 (N.Y. 1986) (upholding the right of institutionalized mentally ill patients to refuse forced treatment with antipsychotic drugs).

81. See text accompanying note 72, *supra*.

82. Campbell and Glass, *supra* note 72, at 486.

83. K.M. Gatter, "The Continued Existence and Benefit of Medicine's Autonomous Law in Today's Health System," *Dayton Law Review* 24 (1999): 220. Gatter borrows the term "autonomous lawmaking" from Weyrauch and Bell. *Id.* at 223. Writing approvingly of the medical profession's culture of self-regulation, Gatter argues that "[c]ourts, legislatures and others ought to recognize that the prohibitive characteristics of medicine's rule against medical malpractice benefit patients and the administration of health care generally." *Id.* at 282.

84. Campbell and Glass, *supra* note 72, at 475.

85. 464 F.2d 772, 786 (D.C. 1972) (rejecting the notion that "the prevailing fashion within the medical profession" defines the scope of the physician's duty to disclose).

86. *Id.* at 784.

87. In terms of the deference historically shown by the legal system to the medical profession in matters concerning the treatment of patients, the United Kingdom does not differ greatly from the United States. According to H. Teff, "the instincts of the [British] judiciary and their actual decisions reveal a marked preference for leaving the medical world to its own devices." Parliament tends to be similarly non-interventionist:

... [T]hough some statutory developments undoubtedly have an effect on the way doctors treat patients, Parliament has rarely sought to interfere directly in medical relationships and dictate the terms. As far as the civil liability of the medical profession is concerned, over many centuries it has been the law's lack of engagement with medicine which is most noteworthy.

Teff, *supra* note 61, at 34.

88. The state's expert witness (a plastic and reconstructive surgeon) in *People v. Brown*, 91 Cal. App. 4th 256, 262 (2001), testified that performing elective amputations constitutes a breach of the professional standard of care. "No competent physician," he asserted, "would amputate a healthy leg for no medical reason." *Id.*

89. See text accompanying note 6, *supra*.

90. Dotinga, *supra* note 5.

91. G.J. Agich, "Ethics and Innovation in Medicine," *Journal of Medical Ethics* 27 (2001): 295.

92. *Id.*

93. *Id.*

94. *Id.*

95. *Id.*

96. Agich, *supra* note 91, at 295.

97. Dyer, *supra* note 1, at 332.

98. Agich, *supra* note 91, at 295 (quoting paragraph 30 of the Declaration of Helsinki).

99. *Id.*

100. See Fisher and Smith, *supra* note 40, at 1147.

101. J. Johnston and C. Elliott, "Healthy Limb Amputation: Ethical and Legal Aspects," *Clinical Medicine* 2 (2002): at 431-435.

102. C.E. Margo, "When is Surgery Research? Towards an Operational Definition of Human Research," *Journal of Medical Ethics* 27 (2001): at 42.

103. *Id.*

104. *Complete Obsession*, *supra* note 7. See also Dotinga, *supra* note 5.

105. Johnston and Elliott, *supra* note 101.

106. T.N. Wise and R.C. Kalyanam, "Amputee Fetishism and Genital Mutilation: Case Report and Literature Review," *Journal of Sex and Marital Therapy* 26 (2000): at 339-340.

107. See *People v. Brown*, 91 Cal. App. 4th 256 (2001), at 260. The surgeon who performed the amputation on Philip Bondy for a fee of \$10,000.00 had twice failed to qualify for board certification in general surgery and was unlicensed at the time of the surgery, having had his medical license revoked by the State of California for gross negligence. *Id.*