

Apotemnophilia: ethical considerations of amputating a healthy limb

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ABSTRACT

Apotemnophilia is a condition that causes those who have it to not feel “correct” in their own bodies. As a result, an intense obsession develops with removing the limb; this obsession hinders tremendously the patients’ social behaviour and societal integration. These patients, in some respects resembling transgendered individuals, feel that the body part (limb) in question is simply “not a part of themselves”, causing them to feel uncomfortable in their own bodies. Whether amputations should be performed on apotemnophiles or not is a question that poses a significant medical ethical dilemma. It is argued that observing an apotemnophile’s request for amputation is the ethical action. The major arguments opposing such amputations and supporting such amputations are examined and critically analysed with regard to ethical principles—namely, patient autonomy, beneficence, non-maleficence and justice with regard to every person’s “right to happiness”. Finally, a discourse on how the accepted notion of *harm* does not apply to apotemnophilia is developed to justify the position that amputation is indeed medically the ethical choice.

In 2000, controversy swept the UK when a Scottish surgeon, Dr Robert Smith, disclosed the fact that he had amputated the limbs of two perfectly able-bodied people at their own request and without any monetary compensation.¹ Because of concern about the legal and ethical implications of such surgery, the National Health Service removed his funding and he was prevented from amputating the limb of a third patient who approached him with a similar request.¹ A psychiatrist, prior to any surgical intervention, diagnosed these patients as having “apotemnophilia”, a condition that causes those who have it to not feel “correct” in their own bodies.² As a result, such patients develop an intense obsession with removing the limb, which greatly hinders their social behaviour and societal integration.³ These patients, in some respects resembling transgendered individuals, feel that the body part (limb) in question is simply “not a part of themselves”, causing them to feel uncomfortable in their own bodies.^{3,4}

AIM

Whether amputations should be performed on apotemnophiles or not is a question that poses a significant medical ethical dilemma.⁵ I believe that observing an apotemnophile’s request for amputation is the ethical action. Here I critically analyse the opposing and supporting arguments, based on a discussion of the ethical principles of patient autonomy, beneficence, non-maleficence and justice

with regard to every person’s “right to happiness”, and develop a discourse on how the accepted notion of *harm* does not apply to apotemnophilia.

WHY SHOULD APOTEMNOPHILES NOT HAVE THE OPTION?

The biggest objection to surgical measures concerns patient consent and the idea that patients requesting such a procedure certainly could not have the mental capabilities that are necessary to give informed consent.^{6,7} The diagnosis of apotemnophilia is fraught with issues in itself, considering that scientific authorities have differing opinions on how to distinguish it from other disorders, such as body integrity identity disorder,⁶ another recognised psychological disorder in which persons may also present requesting the removal of a body part that is seemingly alien to them. According to Braam and colleagues, apotemnophilia is regarded as a type of paraphilia, a psychosexual disorder in which there is a strong sexual urge behind the desire or behaviour.⁷ That being so, “Attempts are made to introduce a more comprehensive definition of the syndrome, described as “body integrity identity disorder,” suitable for the DSM-IV classification, instead of classifying the syndrome as a paraphilia or body dysmorphic disorder”.⁷ Braam and colleagues also state that “Apotemnophilia is encountered without sexual connotations”.⁷ This poses a problem, considering that the core of the definition is based on sexually based connections to the need for amputation.

Nevertheless, if the DSM-IV definition is accepted for argument’s sake, it automatically presents a significant ethical issue, as any type of psychological abnormality inherently insists upon a debate regarding the patient’s capacity to give informed consent. Informed consent is a legal construct whereby a person can be said to have given consent based upon an appreciation and understanding of the facts and implications of an action. To give such consent, patients need to be in possession of relevant facts and also of their reasoning faculties, such as not having a mental disorder or mental illness and not having impaired judgement at the time of consenting.⁸ Inability to make rational decisions due to lack of consciousness or the inability to think rationally because of extreme pain (emotional or physical) is what renders most patients unable to give informed consent in today’s medical community.^{7,8} Opponents of amputation claim that individuals with apotemnophilia, due to their unmet desire to remove the limb, are in emotional pain, and possibly depressed: hence, a rational decision regarding amputation cannot be attained⁹—the obvious prejudice in this claim being the

assumption that anyone wishing for an amputation automatically must be irrational. Psychological and psychiatric evaluations of these patients have proved that they are not only competent, but completely rational beings.^{4 9 10} In fact, a diagnosis of any other psychiatric condition (such as schizophrenia or psychosis) in effect rules out a diagnosis of apotemnophilia.^{9 10} Ramachandran and McGeoch state in their article about body dysmorphic disorder, "Such patients are not psychotic or delusional, however, they do express an inexplicable emotional abhorrence to the limb they wish removed".¹¹ Furthermore, these apotemnophile patients are not at all found to be depressed, as they scored very high in self-esteem assessments and scored poorly only when asked about social issues that stemmed from the fact that they were uncomfortable in their own bodies.⁴ Bayne and Levy⁶ state that patients with body dysmorphic disorder "meet reasonable standards for rationality and autonomy: so as long as no other effective treatment for their disorder is available, surgeons ought to be allowed to accede to their requests".⁶ Ironically, the other leading opposing argument against amputation as medical treatment is based on the idea that these patients are actually completely competent and rational, and are just abusing the medical system in order to fulfil unmet perverted desires, be they sexual or social.⁴ This possibility that medicine will become "a commodity relying on cultivation of desires instead of satisfaction of needs, even as many basic needs go unmet" frightens physicians.¹²

It has been documented that apotemnophiles tend to be sexually attracted to others with amputations or, at the least, consider themselves as more sexually attractive with their amputations.^{3 4 13 14} Hence, it has been argued that performing these amputations would serve merely to aid a form of sexual perversion.^{4 13 14} Lawrence⁴ states that "persons who desire limb amputation ... often assert that that their motives for wanting to change their bodies reflect issues of identity rather than sexuality, but because erotic/romantic orientations contribute significantly to identity, such distinctions may not be meaningful".⁴ As a result, opponents of amputation voice the concern that the medical profession would just be expending time and resources to fulfil the fetishes of a tiny group of individuals while the "real" patients (eg, coronary, hernia) would be forced to stay on a waiting list until resources become available.^{3 6} The problem with this argument is that it inherently assumes that the sexual aspect, while possibly present, is the only reason that apotemnophiles want the procedure. A component of good sex involves both parties feeling comfortable in their own body and a sense of security in sharing their shape and form with their partner. Hence, could it be that since the defining characteristic of an apotemnophile is total insecurity and disgust with their physique, redefining that body shape to fit the "correct" form would certainly make sex better, as otherwise they are not comfortable and do not feel sexually appealing?² People when sexually fantasising often imagine themselves to be thinner, prettier or perfect according to their standards. Why would this behaviour be different for the apotemnophile? Naturally, when sexually fantasising they see themselves as "perfect" according to their own standards, which includes an amputation.^{3 4 6 15}

Let us even go so far as to assume for a moment that apotemnophiles do indulge in amputation for purely sexual gain. What is cosmetic surgery except a legal and medically acceptable way to attain sexual perfection with regard to body image? The argument supporting cosmetic surgery is that patients, after being told of the potential risks, have the right to decide what happens to their bodies and deserve the right to be psychologically content.¹⁶ A child who is seriously disfigured as a burn

victim would have no problem in today's society rallying support for a cosmetic procedure on the basis that he would be "psychologically destroyed" because when looking in the mirror he would insist that "his face was not his own".¹⁶ Similarly, apotemnophiles feel their body to be alien, so what is the difference between a child with a burn and a child with an "extra, alien arm", as an apotemnophile would put it? Do they not both have the right to have appropriate cosmetic surgery to alter their shape according to what they perceive as their own body and, therefore, "normal"?

This brings up the most important argument to support amputation for an apotemnophile. Having the right to one's own being and own ideals, whether physical or mental, is what is termed *autonomy*.¹⁷ Within these contexts, it refers to the capacity of rational individuals to make informed, uncoerced decisions regarding themselves.¹⁸ Without question, patient autonomy is the strongest reason for the ethical justification of amputation.^{19 20}

WHY SHOULD APOTEMNOPHILES BE SUPPORTED IN THIS OPTION?

Basically, assuming the apotemnophile is pursuing the procedure with the utmost competence and without any vulgar intentions, at what point do the moral and ethical considerations of the surgeon trespass on the rights of the patient, namely, the right to patient autonomy? In our medical community, it is deemed "unethical" to force a procedure, regardless of the fact that it has lifesaving capability (eg, giving a blood transfusion to a Jehovah's Witness), on a competent patient if the patient has denied consent.^{16 20} This doctor-initiated autonomy is based on the idea that the doctor suggests the regime. Using similar reasoning, should it not be unethical to deny a particular procedure to a patient if it is sure to correct the underlying ailment? In the USA, *Bartling v Superior Court*²¹ ruled: "Adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn."²¹ This decision was based on the Millian concept of autonomy, which asserts that "over himself, over his own body and mind, the individual is sovereign".¹⁶ The result of all this is that logic dictates and physicians follow the deduced ethical code that they must therefore respect the patient's wishes when refusing potentially life-saving treatment.

The obvious question, then, is whether the same respect from physician to patient should be applied when a patient is not refusing but requesting treatment. Apotemnophiles stress that from a very early age, in some cases as young as 5 or 6 years, they feel like their bodies are not "theirs", with all of them reaching the conclusion that they want amputations by adolescence.^{4 6 19} There are many theories for this "apotemnophile phenomenon", ranging from amputee imprinting to brain deformities that cause a lack of proprioception in the afflicted limb. However, from an ethical standpoint there is no point in discussing the reasons why apotemnophilia exists, because it will not change the fact that it does exist, and the result, regardless of why it came about, will consistently be the need for an amputation as the only acceptable treatment regime.²⁻⁴ If one has lung cancer, it is futile to spend hours mulling over the question of why it came about; the treatment regime as pertinent to the patient will alter only negligibly according to whether genetics or smoking was the main cause of the cancer. Similarly, all paths that lead to apotemnophilia converge at the point of amputation as treatment. Apotemnophiles do not allow themselves the luxury of "no amputation" as an alternative.^{20 22 23} The only

options are either that a surgeon does the amputation in a safe environment or that the apotemnophile will conduct an amputation at home or in a “back-alley” fashion, where the person’s life would be put at a serious risk.²³ There have been numerous discussions of how apotemnophiles have threatened suicide; indeed, Dr Smith warned of the dire consequences of not respecting the decisions of these patients; he is quoted as saying that because “they may take the law into their own hands, they may lie on a railway line and get run over by a train. They may use shotguns and shoot their limbs off ... they are quite a desperate bunch.”²² Cases that have made headlines include the tragic case of Mr Phillip Bondy, who paid a surgeon, Dr Brown, US\$10 000 for an amputation of his healthy leg in 1998.²⁴ Bondy subsequently died of gangrene poisoning in a San Diego hotel two days after the operation.²⁴ Another case in the USA consisted of a 55-year-old man using a home-made guillotine to chop off his arm, which he placed in a freezer bag.²⁵ After calling the paramedics, he was taken to hospital and was told his arm could be re-attached.²⁵ However, he insisted that no such action should be taken and even threatened to sue the hospital for battery if they tried to re-attach the arm.²⁵ The level of competence of this man, and of others that have gone to such great lengths to execute such an operation, cannot be denied.

What is even more convincing is that most apotemnophiles are extremely happy post amputation. In 2000, the BBC²² interviewed one such patient, who said, “It improved my life quite a bit ‘cos that’s the way I wanted to be, that’s the way it is so I am quite happy about it ...”²² Psychologists have reported, on the basis of follow-up case studies, that people who choose to have their legs removed receive an incredible amount of psychological good after amputation, which, naturally, gives them a greater sense of joy and fulfilment from life.²³ This takes one back to the question of patient autonomy. Apotemnophiles claim that the only acceptable treatment for their condition involves an amputation of some sort.^{23 26} Hence, in summary, just as a patient can refuse treatment, is it not fair for these patients, in a completely acceptable stance on autonomy, to request this treatment? Furthermore, if, as stated above, amputation is denied, and patients are forced into illegal means of attaining treatment (a.k.a. amputation), does that not breach the ethical code of non-maleficence (do no harm) and beneficence (the duty of a physician to patient welfare) demanded of any practising physician?²⁷

NON-MALEFICENCE AND BENEFICENCE

In order to address the question of *primum non nocere*,²⁸ or “do no harm”, the concept of *harm* needs to be described as it pertains to the case of the apotemnophile.²⁸ *Harm*, in the conventional sense, places undue stress on the physical being of a patient without taking into account the mental. The idea of neglecting the psychological being when discussing *harm* in the medical sense of the word can have dire consequences.²³ Opponents of amputation argue, quite rightly, that unnecessary surgical intervention on a patient is wrong, as it violates the non-maleficence aspect of medicine.²⁷ Surely, putting a patient at unnecessary surgical risk is immoral and does, in fact, constitute harm.²⁷ However, the question in this case is not about whether amputation is a surgical risk, but whether or not this type of operation is “unnecessary”. There is no question about the psychological impact of apotemnophilia on a patient. Dr Smith¹⁰ stated that “at the end of the day I have no doubt that what I was doing was the correct thing for those patients”¹⁰. He went on to say, “The Hippocratic oath says first do your patients no harm, but maybe the real harm is refusing to treat such a patient leaving

him a state of permanent mental torment when all it would take to live a satisfied and happy life would be an amputation.”²² Dr Smith added that although these patients were fitted with prosthetic limbs, they rarely if ever used them, stressing the point that amputation was truly what they wanted.^{10 23} Dr Russell Reid, a psychiatrist from London, stated, “Psychotherapy doesn’t make a scrap of a difference to these people.”^{9 22} Harm, therefore, cannot be looked at from a traditional perspective when deciding whether amputation as a therapy is harming the patient or helping, because the conventional view of harm does not take psychology into account. If one were to take into account the psychological torment faced by apotemnophiles, perhaps not agreeing to perform the amputation would go against both the concept of “do not harm” and the duty to contribute to the patient’s welfare as a physician, in other words, beneficence.²⁷

DISCUSSION

The moral obligation, especially as a physician, to act for the benefit of others first has to determine whether said act is truly for the benefit of others—that is, does it bring happiness to the patient. The best way to address the idea of “happiness” is through utilitarian guidance.²⁹ As an ethical code, utilitarianism is founded on the maximum amount of happiness to the greatest number of people.²⁹ This is in contrast to the Kantian philosophy, which takes into account the “rights” of the individual strictly.²⁹

Medical harm is most important when discussing what brings about the most happiness to a population versus the absolute of the “right”; hence, a utilitarian ethic is a much more appropriate prism through which to view the principle of harm.^{20 29} Although apotemnophiles are rare, their healthy limbs can be donated to individuals who may have accidents necessitating the donation of another person’s limb.⁵ Although this science has not caught on at present, the potential is there and this would, in turn, benefit society as a whole. Simultaneously, the apotemnophiles of society would maintain their happiness and be contributing members of the community, a role they cannot manage without corrective amputative surgery.²³ One of the characteristics of an apotemnophile is the desire to do great things for society in spite of the missing limb.^{23 30} Hence, the opposition’s view that these individuals would just become disabled individuals collecting benefits and imposing on society can be silenced immediately. The majority of apotemnophile amputees have been logged, and almost all the patients re-entered society as successful and contributing members, once again upholding the utilitarian perspective of greatest happiness and benefit to the society as a whole.²³

The extraordinary thing about the apotemnophilia debate is that, unlike traditional ethical discussion where utilitarianism and Kantianism are in opposition, this debate lends itself to the support of both sides. Basically, Kantians believe that the “rights” of the individual are always meant to be the focus, regardless of the betterment of society as a whole.²⁹ Therefore, the “right to individual happiness” is paramount, and a Kantian physician should be asking “What will raise my patient’s happiness for the longest period of time?” and, secondly, “Is the risk to the patient’s happiness so great as to necessitate drastic measures?” As stated earlier, patients have gone to extreme measures to attain their amputations, leading to death for some.^{23–25 30} Furthermore, successful amputees claim that their lives have been restored to normality and that without the amputations they would have remained miserable.^{22 23} Basically, no matter how their bodies may physically be after amputation, it is immaterial to the apotemnophile’s happiness. Thus, Kantian philosophy that insists that the individual right to happiness is of

utmost importance can be wholeheartedly applied to the case of the apotemnophile, since the only way to bring about the individual's happiness is through an amputation and nothing else.

CONCLUSIONS

Overall, regardless of whether a utilitarian or Kantian view is adopted, providing apotemnophiles with the opportunity to undergo a safe medical procedure resulting in amputation fulfils the requirements of both views—simultaneously benefiting the society by allowing the maximum amount of happiness for the majority and maintaining the individual's right to happiness. The principles governing physicians' ethics, namely patient autonomy, non-maleficence and beneficence, are all honoured by proceeding with amputation for a patient who will suffer immensely without it.

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Anahita Dua is a student in her final year of medical school at the University of Aberdeen.

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