

APOTEMNOPHILIA: A COMPREHENSIVE OVERVIEW

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Abstract

This paper describes apotemnophilia, a rare condition in which an otherwise healthy person has a strong desire to amputate a healthy body part. This article aims to increase awareness about the condition and extend the knowledge base of health professionals and the general population. The study involved an extensive search of the literature on the epidemiology, aetiology, symptoms, diagnosis and management of this condition. It was found that the desire to get rid of a limb can get overwhelmingly strong that the patients try to amputate themselves at a specific level. This is usually a result of the feeling of mismatch between the actual physical appearance and perceived true self of the individual. These thoughts cause distress which can disrupt the social life of those affected and distract them from their daily activities. The paper also describes the possible causes of apotemnophilia which can be psychological or neurological. Furthermore, it highlighted a set of diagnostic criteria that characterise this condition. Although there is no proven effective treatment; psychotherapy and pharmacotherapy are the mainstays of treatment.

The article reveals the need for further studies to investigate the perception of the general population about apotemnophilia and offers recommendations for improving the management of the condition.

Keywords: Apotemnophilia, Amputation, Amputee, Mental Health.

Cite this article: Akano OT, Oduguwa IO. Apotemnophilia: a comprehensive overview. Yen Med J. 2021;3(1):12–16.

INTRODUCTION

Apotemnophilia denotes a syndrome or symptom complex in which an otherwise sane person is preoccupied with a strong desire to amputate a healthy body part.¹ The wish for amputation by a healthy person was coined "apotemnophilia" by Money, Jobaris, and Furth.² It has been reported that the desire to be paralysed is another variant of apotemnophilia.³ John Money described in 1977 two individuals who wanted to become amputees because they were sexually aroused by this idea. He coined this condition as apotemnophilia, asexual deviation, or paraphilia, in which a stump, pair of crutches, or wheelchair is eroticised. First classified it as a kind of identity disorder and developed the term "Body Integrity Identity Disorder" (BIID).⁴

In most instances, the preoccupation entails the amputation of one's arm or leg at a specific and definite level. The desire to get rid of a limb can get overwhelmingly strong that patients try to do it

themselves.⁵ People with apotemnophilia have a mismatch between their actual physical appearance and their perceived true self. They feel being an amputee will make them 'whole'. Reports of emotional detachment or discomfort towards the particular appendage are common, and they usually have a compulsive wish to cut it off, because it feels strange to what they believe truly represents their body schema. Many are distressed by such thoughts, which can disrupt their social life and distract them from their daily activities.⁶⁻⁸ In a particular study,¹ 9 out of 52 patients had an arm or leg amputated, with two-thirds using methods that put themselves at risk of death.

This article aims to increase awareness about the condition and extend the knowledge base of health professionals and the general population.

EPIDEMIOLOGY

Apotemnophilia is a very rare condition, and accurate numbers for the occurrence in the general population are

undetermined. This is probably due to most cases being under-reported because patients do not want to live with the stigma of being tagged insane or abnormal.

The onset of this desire typically occurs in childhood or adolescence at a mean age of 6-7 years.³ It is associated with chronic feelings of dysphoria which are relieved by the desire to seek surgical intervention or to pretend to have the acquired disability. Males seem to be more likely to be affected than females, but the ratio is undefined.⁹ Majorly, patients desire the amputation of either a left-sided limb (55%) or both limbs (18%), while the minority (27%) only want the removal of the right-sided limb (Table 1).⁴ First also found that up to 67% of study participants with BIID desired amputation ‘in order to feel sexually satisfied inside’ and nearly one-third had at least 1 further paraphilia.⁴

A study done by Blom, which surveyed 54 individuals with the age range of 18–76 years, reported findings consistent with First’s; 80% of the participants interviewed were male, and over 90% were white.³ Two-thirds were educated to university degree level. Forty-four percent (44%) reported a wish to be disabled but not through amputation. They desired non-functioning limbs instead and specified the location of their choice.³

Table 1. Reasons for amputation⁴

| Reasons | Percentage that endorsed as important reason (n=52) |
|---|---|
| ‘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) |

ETIOLOGY

People who suffer from apotemnophilia mostly date the desire for amputation to childhood and often struggle to explain how it all started. Traditionally, the cause of apotemnophilia has been considered to be strictly psychological with explanations of it being a sexual

paraphilia, due to the supposed phallic resemblance of an amputee’s stump. It has also been suggested that the sight of an amputee at a young age creates a permanent picture of an ideal body image in the subconscious of a child, as well as an attraction to people with amputation.¹⁰

However, recent studies have shown that the basis is neurological, because sufferers show no signs of psychosis or delusions. They are sane; they know their wants are abnormal,^{10–14} and they usually want amputation of their limbs at a specified level. It has also been established that there is a left-sided preponderance in this condition similar to what obtains in somatoparaphrenia, a condition in which a patient with a parietal lobe stroke denies ownership of his contralateral limb.¹⁵ Brang reported evidence of heightened skin conductance in response to pinprick below the level of the desired amputation in two individuals who had a longstanding wish for amputation of their limbs.¹⁰

This was explained as arising from a congenital dysfunction of the right superior parietal lobule and its connections to the insula. Lenggenhager et al also reported evidence of reduced cortical thickness in the superior parietal lobule and reduced cortical surface area in the primary and secondary somatosensory cortices in the inferior parietal lobule, as well as in the anterior insular cortex.¹³

SYMPTOMS

The following clinical features have been identified in patients with apotemnophilia:^{1,3,4,16,17}

1. Persistent desire for amputation.
2. Disturbance in social and occupational functioning.
3. Pretentious acts of being disabled.
4. Attempt to self-amputate.
5. Sexual attraction to other amputees.

DIAGNOSIS

Diagnosis of apotemnophilia is difficult because formal diagnostic criteria have not been established, and this makes identification of the condition challenging. At present, it is not included in the Diagnostic Statistical Manual 5 (DSM-5) as a recognized disorder. However, First and Fisher¹⁶ proposed a set of

diagnostic criteria that highlight key characteristics of this condition.

These include:

1. Early-onset as a child or adolescent,
2. Intense and persistent desire to become an amputee or to acquire a form of disability,
3. Discomfort with one's current physical appearance and body schema,
4. Overbearing preoccupation with thoughts of amputation that affects normal social and occupational functioning,
5. Attempts to self-amputate or become disabled.¹⁶

Importantly, apotemnophilia must be identified as distinct from any other psychotic processes, neurological conditions, or mental disorders.¹⁸

MANAGEMENT

As there is no proven effective treatment for people with apotemnophilia to date, some patients resort to self-amputation leading to serious complications or death. The mainstay of treatment is psychotherapy or pharmacotherapy. Individuals with Body Integrity Identity Disorder are most likely to be offered a psychological intervention such as cognitive behavioural therapy or psychotherapy as a management option or pharmacological treatment with a selective serotonin reuptake inhibitor or other antidepressant medication.

Cognitive Behavioural Psychotherapy

Several studies of psychotherapy effects and reports of concerned persons showed emotional relief but not a disappearance of the desire for amputation,^{7,9} and traditional psychotherapy has so far been shown to have little effect on this desire.^{4,6,7}

A case study carried out by Braam et al that involved a 35-year-old man with apotemnophilia reported that the patient still desired amputation after about 30 sessions of cognitive behavioural therapy.⁹ Although the time spent by the patient on preoccupied thoughts and pretentious acts about being an amputee reduced, he was still of the opinion that the leg in question didn't belong to him. The

patient was reluctant to explore a future with a complete leg but felt freer to discuss his condition with others.

Pharmacotherapy

There is limited literature on the effectiveness of pharmacotherapy. Pharmacological management can be through selective serotonin reuptake inhibitor and other antidepressants. A trial of fluoxetine in a patient demonstrated a slight reduction in symptoms.⁸ The use of the anxiolytic oxazepam was associated with some reduction in the level of tension and distress in a case study carried out by Braam et al.⁹

Cold Caloric Vestibular Stimulation

Ramachandran and McGeoch¹⁵ proposed that apotemnophilia can be treated with cold caloric vestibular stimulation because of the similarities the condition shares with somatoparaphrenia, as individuals with apotemnophilia show a left-sided preference for amputation. Somatoparaphrenic patients have been reported to experience significant remission of their symptoms when treated with cold caloric vestibular stimulation due to the effects of this technique on the right parietal lobe.¹⁹

Amputation

Courses of antidepressants and behavioural therapy can sometimes lessen the compulsory thoughts of amputation, but do not entirely suppress them.^{9,20} As drastic as amputation is, patients report a sense of completeness when it is done, feeling happier and more enthusiastic about the future. Anecdotally, the realization of the patient's desires as a means of therapy, either as an elective procedure or self-inflicted, is the only effective treatment.⁵ Elective amputation is not usually carried out due to ethical considerations and the costs of living with disability after the amputation.²¹ Despite this, some patients gave accounts of feelings of contentment and joy after the operation.⁵

ETHICAL CONSIDERATIONS

Although it has been reported that amputation is the only effective way of treating apotemnophilia, its use as a form of therapy is deeply troubling. It is argued that if allowed, amputations could eventually lead to the acceptance of

self-harm without meaningful attempts to address the underlying psychological causes of self-loathing.²² In line with the well-established principle of non-maleficence, Beauchamp and Childress²³ argued that amputation of a healthy limb causes harm in form of pain and disability which in turn increase the cost of living of the patient and his level of dependence on people. In addition, the case made by Johnston and Elliot²⁴ was that a surgeon who performs amputation of a healthy limb may be liable to a suit of medical malpractice and charged with criminal assault, because the procedure is not recognized by the appropriate medical bodies as an effective way of managing Body Integrity Identity Disorder.

Alternatively, Bayne and Levy⁷ argued that the request by patients for elective amputation of a healthy limb should be granted because it mitigates harm by securing proper, adequate, and supervised medical treatment, rather than exposing patients to risky, unsupervised surgeries done by quacks. The same view is shared by Blom who suggested that elective amputation can forestall complications and death in patients considering self-amputation.²⁵

RECOMMENDATIONS

Further studies should be done to investigate the perception of the general population about apotemnophilia, especially in African countries where the culture greatly influences people's perception of illnesses. This will help in developing management strategies relevant to the population and region.²⁶ More awareness should be created to enable people seek early psychological evaluation. Psychosocial support services should be provided for patients with apotemnophilia to help boost their mental health status and social integration.²⁷ E-Mental health services may be employed to improve the accessibility of patients with the condition to healthcare services.²⁸

CONCLUSION

Apotemnophilia is a condition whereby an otherwise sane person is preoccupied with desires to amputate a healthy body part. It is characterized by emotional distress that disturbs social and occupational functioning. This condition is rare and the diagnosis is challenging as there are no formal diagnostic criteria included in DSM 5.

Research has shown that apotemnophilia can be managed by pharmacotherapy and psychotherapy but with minimal success. Amputation remains the only form of 'therapy' found to provide long-lasting respite for affected patients.

AUTHOR'S CONTRIBUTIONS

OTA was involved in the conceptualisation of the study, literature search, manuscript preparation and review.

IOO was involved in manuscript preparation and review. Both authors read the final copy of the manuscript.

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