

# A Compelling Desire for Deafness

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A case is described of a patient who has a compelling and persistent desire to become deaf. She often kept cotton wool moistened with oil in her ears and was learning sign language. Living without sound appeared to be a severe form of avoidance behavior from hyperacusis and misophonia. She had a borderline personality disorder that was associated with a poor sense of self. Her desire to be deaf may be one aspect of gaining an identity for herself and to compensate for feeling like an alien and gaining acceptance in the Deaf community. Will a compelling desire for deafness ever become a recognized mental disorder one day for which hearing patients may be offered elective deafness after a period of assessment and living like a deaf person? Those working in the field of deafness should be aware that individuals may occasionally be seeking elective deafness or self-inflicting deafness to obtain a hearing aid.

Self-injurious behaviors (SIBs) are defined as deliberate infliction of direct physical harm to one's body without any intent to die as a consequence of the behavior (Simeon & Favazza, 2001). Major SIBs tend to be isolated events and consists of severe or life-threatening tissue damage, such as self-castration, eye nucleation, or less commonly self-amputation of a limb or ear. They mainly occur in young psychotic men or older males with psychotic depression usually in the context of command auditory hallucinations or delusions of guilt. Less commonly, major SIBs can occur in males with gender identity disorder. In gender identity disorder, individuals feel they have been born the wrong sex and that their genitals do not belong to them. Genital self-mutilation may occur

when such individuals are denied or unable to afford gender reassignment.

This article expands on the category of a major SIB in which the self is identified with being disabled. For example, there is a report of four HIV-negative homosexual men who are attempting deliberately to infect themselves with HIV so that they may join their HIV-infected partner (Morgan & Jones, 1993). They describe one of the four being successful in infecting himself. They had a desire to be together for the partner, not to be left alone, and to be part of the HIV community. A second example is individuals with amputee identity disorder have a compelling and persistent desire for one or more digits or limbs to be amputated (Furth, Smith, & Kubler-Ross, 2000; Smith & Fisher, 2003). They feel that one or more limbs are not part of their "self" (a form of reverse "phantom limb"). Prior to amputation, individuals may live with a wheelchair, crutches, or leg braces. In the face of opposition from surgeons, some individuals hasten amputation (e.g., chainsaw wound) or carry out self-amputation (e.g., on railway lines). Furthermore, patients who have had surgical amputation claim to have had a successful follow-up (Fisher & Smith, 2000). It is argued that amputee identity disorder is therefore more akin to a gender identity disorder in which an individual feels that his or her genitalia do not belong to him or her and that he or she is trapped in a body of the wrong gender. Individuals with amputees have strong communities of support and solidarity. They are accorded many rights and less stigmatized than other groups such as those with a mental disorder. This is a case report of an individual who strongly identified herself with being deaf, with some similarities to gender identity disorder or amputee identity disorder.

The patient gave written consent for her case to be written up anonymously. Correspondence should be sent to David Veale, Centre for Anxiety Disorders and Trauma, South London and Maudsley Trust, 99 Denmark Hill, London SE5 8AZ, United Kingdom (e-mail: david.veale@iop.kcl.ac.uk).

## Case Report

Ms. A is a 36-year-old married woman who works as a technical author; she has a 13-year-old son from a previous marriage. From a young age, she said she was excessively sensitive to any sound that was associated with feelings of irritation and anger. She had difficulty concentrating with background noise but did not experience tinnitus. She was tested to have normal hearing, but she was preoccupied by a persistent and compelling desire to be deaf. She desired medical assistance with a sympathetic surgeon as she did not want to take the risk complications by using methods such as repeated sounding of a claxon horn in her ears or ototoxic drugs. She had been tested as having normal hearing but felt she was a “deaf person in a hearing person’s body.” She would have no desire to wear a hearing aid but was learning British Sign Language (BSL) and attended a Deaf club. She said that when she first started learning BSL, she began to feel that she had “come home in the way a gay person may only fully grasp their sexuality when they find themselves in a gay bar and feel that at last they fit in.” Her husband’s work often took him away for a few days at a time: during his absence she would block her ears with cotton wool moistened with oil. She often dreamed either about being deaf and communicating in BSL or being in a sound-free environment.

Ms. A was generally a solitary person and described two or three acquaintances but rarely socialized. She reported not being close to anyone in her family, and she worked from her home freelance with most of her contact by e-mail. She believed that the advantages of becoming deaf would include having fewer social responsibilities, being more able to concentrate on tasks, becoming more isolated, feeling less distressed and being less preoccupied about not being deaf, feeling more confident, and being accepted into the Deaf community as a deaf person rather than as a tourist. She acknowledged that such a transition would worsen her relationship with her immediate family and make communicating with the hearing world more difficult, but she felt that was their problem. She thought she could easily give up listening to music and adapt her life. She had joined a “deaf wannabe” group on the Internet and had met another

member of the group who desired total deafness, using sign language rather than hearing aids. She reported that many were either in the process of damaging their hearing by various methods and were already partially deaf. Of these, most used hearing aids so they could still lead their normal life. She observed that some members of the group who were not making themselves deaf had a fetishist attitude toward hearing aids and posted pictures of themselves onto the Web site wearing them.

She came from a mixed race of Caucasian and Asian background. She was placed in foster care from the age of 3–4 as she said her mother could not cope. She said her family was very insular. Her parents separated when she was aged 10, and she had lived with her paternal grandfather and stepgrandmother at the age of 13–14. She felt isolated from her peers as a child or joined in with great difficulty. She had worked earlier in her career as a secretary and subsequently as a technical author. Her mother is aged 61, and she remains in regular contact with her. She described her mother in her early years as strict and indifferent, with frequent depression. She described her mother now as being fond and worrying a lot about her and being a lot closer to her than when she was as a child. Her father was aged 56, and she described him as indifferent and showing affection by giving money and presents. She was in regular contact but said he treated her like a small child. She had one brother whom she would occasionally talk to on the phone or by e-mail. She had married at the age of 19 and divorced at 25. She had one son aged 13 who lived with her ex-husband and stayed with her most weekends. She had a past psychiatric history of bipolar disorder and the onset had occurred after his birth. Her second husband was aged 48, and they had been together for about 4 years. She described this relationship as quite distant. He was unhappy whenever she spoke about her desire to be deaf.

Ms. A was interviewed with the Structured Clinical Interview for the 4th edition of *Diagnostic and Statistical Manual (DSM-IV)* for Axis I (First, Spitzer, Gibbon, & Williams, 1996) and Axis II (First, Spitzer, Gibbon, Williams, & Benjamin, 1997). She had not required hospital admission or previously seen a psychiatrist. She was not psychotic and had no command

hallucinations or delusions. She fulfilled criteria for borderline, schizoid, schizotypal, narcissistic, obsessive-compulsive personality disorders. Of particular note was her poor sense of self. She had always felt like an alien and had assumed different personalities and clothes or voices to fit in with different groups. She avoided crowds or being in groups, especially women, whom she found too intrusive. She had seen an analytical therapist for 6 months, currently twice a week. She reported therapy to be supportive and helpful in gaining a better understanding of herself. She had no desire for any formal psychiatric treatment or to overcome her desire to be deaf.

### Discussion

No previous cases of deliberately self-induced or medically assisted deafness have been described in the literature. Ms. A had not yet proceeded with inducing deafness but had gathered information on suitable methods from an Internet group. She was worried about the risks of tinnitus and other complications and therefore wanted to know whether it was possible to obtain surgically assisted deafness. She cited the cases of limb amputation and gender transformation. She was prepared to live as a deaf person with cotton wool and adapt her home for whatever time it took to adjust and convince others of the seriousness of her request. She was prepared to pay privately and believed that there must be at least one surgeon who had carried such requests but that he or she would have shied away from any publicity. She had no desire to be disabled so she could apply for disability benefit. There was no evidence of Munchausen's syndrome or "secondary gain" as she did not want attention from others and strived to isolate herself. My opinion to Ms. A was that no psychiatrist would sanction elective deafness and that no surgeon would assist her in her desired goal.

There was no particular connection with the Deaf community in her past, and Ms. A seemed to have two main strands in her desire for deafness. First, she manifested an extreme form of avoidance behavior in response to hyperacusis and misophonia. Hyperacusis is an abnormally strong reaction to sound occurring within the auditory pathways. Individuals are unable to tolerate ordinary levels of noise and experience phys-

ical discomfort as a result of exposure to sound (irrespective of the volume). In Ms. A's case, repeated avoidance of sound would have led to increased auditory gain (amplification) in her auditory pathway and worsening of her symptoms. Misophonia and phonophobia are defined as abnormally strong emotional reactions to sound through the limbic and autonomic nervous system without any significant activation of the auditory system (Jastreboff, 2000). Misophonia is an extreme dislike or hatred of sound. Phonophobia is a specific type of misophonia in which fear is the dominant emotion. Jastreboff and Hazell (2004) have developed a program (a) for treating hyperacusis by desensitization using systematic graded exposure to nonannoying sounds that result in increased threshold for discomfort and (b) for treating misophonia by extinction of a conditioned reflex by systematic exposure to recorded pleasant sounds to which the patient has to pay attention. I discussed such a program with Ms. A, but she felt that the treatment was too similar to aversion therapy or "retraining" a gay person to become "the norm" of being heterosexual and that the alternative of becoming deaf was not being seriously considered.

A second strand in her desire for elective deafness is her abnormal personality. The desire for elective deafness and her belief that she is a deaf person in a hearing person's body can be regarded as an overvalued idea, which was derived from idealized values (Veale, 2001). She has a strong lack of identity and self, and her desire for deafness appeared to be one aspect of an attempt to gain an identity to compensate for feeling like an alien and a desire for isolation, fewer responsibilities, and being accepted in the Deaf community. The desire for isolation is of course contradictory to notions of connection and communication within the Deaf community.

Will a compelling desire for deafness ever become a recognized mental disorder for which patients may be offered elective deafness after a period of assessment and living like a deaf person? The desire for elective deafness is in the author's view a new "symptom" or abnormal coping mechanism rather than a new disorder. However, individuals with gender identity disorder have fought to achieve recognition and gender reassignments, and patients with amputee identity disorder now campaign to obtain elective amputation. It is

not inconceivable that elective deafness could one day be offered to such patients as a logical extension of patient choice and acceptance of diversity and avoidance as a means of coping. Such cases are likely to remain extremely rare, but a survey on the Internet group of deaf “wannabes” is now being undertaken. Those working in the field of deafness should be aware that some individuals may be seeking elective deafness or self-inflicting deafness to obtain a hearing aid.

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