

CASE TEACHING NOTES

for

“To Be Who I Am: An Issues Case on Identity and the Body”

by

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INTRODUCTION / BACKGROUND

This issues case centers on a scenario written as a first-person narrative. The narrative, which takes a reflective, highly abbreviated life history approach, describes an individual's desire to become an amputee. John Money, a sex researcher and professor of pediatrics and medical psychology at Johns Hopkins University, first named and wrote about the condition. He classified it as sexual fetishism, labeling it “apotemnophilia” (Money, Jobaris, and Furth 1977). The extent to which sexual desire is at its roots, however, is a subject of debate (Elliott 2000; First 2004). In searching for a way to understand the desire to remove a healthy limb, the condition has been compared to Gender Identity Disorder, whereby an individual's gender identity does not match the gender associated with the individual's physical body (Bridy 2004; Elliott 2000). Others, terming the condition Factitious Disability Disorder, have framed it as something akin to Munchausen's Syndrome, where an individual seeks to become an amputee to fulfill a need for attention and caring from others (Bruno 1997). The condition has also been referred to as “amputee identity disorder” (Furth and Smith 2000) and, most recently, First (2004) makes the case for terming it “body integrity identity disorder” (BIID). This latter acronym is used in these teaching notes for simplicity.

The scenario used in this case is a composite of quotes and sentiments expressed by multiple individuals and culled from a number of articles on the topic (Elliott 2000; Elliott 2003; Henig 2005).

I developed this case following my participation in the May 2005 Case Studies in Science Workshop at the University at Buffalo. In addition to piloting the case at the workshop, I have used it in an Introduction to Sociology course as well as in a sophomore-level Social Psychology course. This interdisciplinary case could be used in other social science courses, such as Abnormal Psychology or Social Deviance, as well as in courses in Disability Studies or Medical Ethics, among other fields.

I run this case in a 50-minute class period and so I find it helpful to have addressed (at least some of) the sociological theory and concepts in advance. In the sections below I make suggestions for additional discussion points that can be added or deleted as warranted by the specific objectives of the course and the time available.

Objectives

- Expose students to a sociological phenomenon with which they are likely unfamiliar.
- Explore factors that play a role in the creation of identity and self-concept.
- Develop capacity for empathetic understanding (Weber's *verstehen*) as a basis for a more nuanced study of social phenomena.
- Compare and critique cultural attributions of deviance to different forms of body modification.
- Identify the apparent contradictions inherent in a desire condemned as deviant by society, yet expressed in terms of values widely promoted by that society.

- Identify how the social forces discussed (attributions of deviance, identity and self-concept, empathetic understanding, larger societal values) shape, and play out in, the lives of students.

CLASSROOM MANAGEMENT / BLOCKS OF ANALYSIS

This is an unfamiliar and seemingly “radical” case; it is likely to elicit strong reactions from students, leading some students to condemn and dismiss the individual(s) involved as “sick” and as “other.” For this reason, it may be most productive not to start with the case scenario itself. Rather, I have found that it is helpful to lay some groundwork that will draw students in and allow for consideration of some of the more subtle and ambiguous issues this case raises.

Laying the Groundwork

One way to set the stage for the scenario is to begin with the following exercise. Ask students to list the different ways an individual might modify his or her body in concert with his/her identity (you may need to explain what “in concert” means: “to express,” “to reflect,” or “as a consequence of”).

Have students first make a list individually, then discuss their lists briefly in pairs, then conduct an “idea census” with the whole class. An idea census involves going around the room and having each student contribute an idea in turn until all ideas have been exhausted. The parameters are as follows:

- A person may contribute only one idea per turn. After each person has had a first turn, proceed around the classroom again. As long as students still have ideas to contribute, the census continues.
- There is no pressure: if a person’s list or ideas are exhausted, he or she may say “pass” and it will be the next student’s turn.
- The professor writes ideas up on the board, may ask a student to explain or elaborate if her/his idea is unclear, may help a student with articulating an idea, but otherwise remains in the background during this exercise.

This exercise serves a number of purposes in the context of this case. First, conceptually, it allows students to start with the familiar, the everyday, their own experiences. It provides them an entry point into a fairly difficult topic, situating *them* in the material. Second, the exercise acts as an icebreaker since it is an “easy” question on which every student will have something to say. Third, the exercise involves all students, from all parts of the room, in generating the list; the list thus becomes a group creation.

Students are often surprised at the extent of the list, which might include the following:

- Hair: cut, color, perm; facial hair: shave, grow beard, wax, pluck (eyebrows, for example)
- Dress: style, expense, uniform (indicating membership, role, or status within an organization or religious community, for example), footwear
- Jewelry, make-up
- Piercings, tattoos, tongue split
- Glasses, contact lenses
- Body-building/sculpting
- Drugs: diet, steroids (some students also suggest that street drugs can give someone a certain “look”)
- Surgery: breast augmentation/reduction, botox, facelifts, etc.
- Cutting, scarification
- Cyberkinetic implants (for the science-fiction minded!) Relatedly, other kinds of implanted devices, such as stents, pacemakers, or artificial joints, can affect one’s identity in terms of a sense of health/fragility and one’s awareness of situations such as airport x-ray devices (though note that this reflects the

opposite relationship between identity and the body as posed in the question)

- Dieting, bingeing, purging
- Vasectomy, hysterectomy, pregnancy
- Nicknames (unlikely-sounding as a type of body modification, yet one student argued that a 6' 4", 250-lb. man might be viewed physically in a very different light if his nickname were "Princess")

Depending on the time available and the particular teaching objectives for this case, additional discussion related to the list generated by the class might include the following:

- "In what different categories might these items be grouped (e.g., permanent versus temporary, common versus rare, healthy versus unhealthy, health versus beauty, etc.)?" These categories can be useful referents in analyzing the case and pushing students to articulate why the scenario should or should not be considered similar to the modifications the class grouped in a particular category.
- "Which of the items in the list are considered 'normal' and are accepted (or conversely, deviant and unaccepted) by the society at large?" Designating a few points on a continuum from "most" to "least" and recopying the items under each point according to the sense of the class (or subsequent to small group discussion) can be helpful here.
- "Are some items viewed differently by different groups within society (e.g., youth versus adults, working class versus middle or upper class)? How do you know this (what suggests to you that this is the case)? Who makes that determination?" This discussion sets a backdrop for interrogating the attribution of the "deviant" label to the scenario, which most students are wont to do.

Presenting the Narrative

Give the students Part I of the case, entitled "Narrative." Instruct students as follows: "As you read, circle or underline words and ideas that catch your attention; make comments on your reactions in the margins." Alternatively, you can ask one or more students to read the narrative aloud to the class rather than having students read silently to themselves.

Ask students in groups of three to four to discuss their initial reactions to the scenario. Students most often mention mental illness, pity, and achievement as associations that come to mind.

Depending on your goals for the discussion, you might ask them how wanting to be an amputee is different from wanting to have cosmetic surgery or other items on the list on the board that the class generated earlier. (If you extended the discussion to categorization, you can draw on the results of that exercise here.)

If they offer negative judgments, press the students to identify, specifically, what bothers them about the notion or what the basis is for their negative evaluation. Use this to talk about their own cultural socialization—what are the norms and values they have been taught that are violated by the idea of wanting to remove a healthy limb. (If you extended the discussion to attributions of deviance, make connections here to ideas raised in that exercise.)

Since a main substantive issue in the scenario involves disability, it is helpful to address this directly. Two points, in particular, are key. First, students' reactions in large part reflect a societal fear of disability and the "disabled state." If being disabled is just another social characteristic, similar, say, to "divorced" or "college graduate," then why would we have such a reaction in our gut when someone announces her/his intention to enter this state (become a person with a disability)? Fearing disability, and not viewing it as a normal part of life, reflects the assumptions of the medical model, as discussed by researcher Carol Gill and others (Gill et al. 2003). The medical model assumes disability resides not in societal interactions and labels, but

in broken bodies. These bodies are in need of fixing by professionals, with the goal of attaining—or at least approximating as much as possible—a non-disabled state (the debate over the use of cochlear implants for deaf children, e.g., illustrates these two approaches).

Second, also related to the subordinate social status of persons with disabilities, is the scenario's reference to "overcompensating" and "exceeding expectations." The object of desire, the image of the "supercrip," is rooted in the pervasive treatment of persons with disabilities as helpless, incompetent, and objects of pity (Golfus 1994). It is against this background of little or no expectations that a person who has a disability gets lauded for accomplishments normally seen to be within the reach of an average adult. One might liken this to the praise given men appearing in public with children in strollers—"what a wonderful father," "isn't his wife lucky?" etc., while women are not seen in a similar light because caring for children is simply expected of them as a matter of course (see Deutsch 1999).

Thus, the scenario draws on problematic images of disability in two ways. It evokes reactions based on negative images of disability pervasive in U.S. society, and it reinforces the notion that persons with disabilities are not competent adults whom we might expect to be active in all walks of life—as employees, athletes, lovers, business owners, educators, parents, etc. In addition, a third dynamic is also at play, highlighted by individuals who became amputees through traumatic injury or illness: many amputees live with chronic pain and ill-fitting prostheses. These individuals may find that the rhetoric of BIID, as illustrated by the scenario, minimizes their experience by portraying amputation as an identity "choice" (Henig 2005).

Presenting the Theory

At this point, to introduce theory into the discussion, I produce a rather catchy and attention-getting quote from social psychologist Charles Horton Cooley, written on the board or projected for the class to see:

*"Each to each a looking-glass
Reflects the other that doth pass."*

I like to joke that not all sociology theory is written in meter and rhyme, and approximates Shakespeare in its articulation!

I ask students to discuss in their groups of three to four students what the quote means and how they can relate it to the scenario. Depending on the size of the class, each group can share ideas with the class, or a few groups can be selected to do so, with other groups being asked afterwards if they have any additional thoughts to add.

I then pass out Part II as a handout, which contains an excerpt from Cooley's theory of the "looking-glass self," elaborating on the above quote. Students can read independently or selected students (or the professor) can read the excerpt aloud to the class. This passage yields rich discussion as students are asked to identify how the three elements of the theory play out in relation to the BIID scenario.

Finally, the discussion can come full circle by asking students to look back at the original list of body modifications, choose one that they have personal experience with, and discuss (e.g., in small groups or in a written essay) how the elements of the looking-glass self theory shaped the decisions they made with respect to that aspect of identity and self-presentation. Students can also be asked to compare their discussion of the looking-glass self with respect to the scenario and to their own experience.

Extensions to this Case Study

Those desiring to use this case for further exploration in a variety of areas might consider the following possible extensions of the material beyond what is described above. Another excellent resource is a documentary by Melody Gilbert, *Whole* (2003), which provides a multifaceted exploration of BIID from the perspectives of individuals with the condition, their family members, and health professionals.

Social research methods (qualitative and/or quantitative)

Since the scenario presents an abbreviated, if conceptually rich, synopsis of one individual's experience, questions like "What else would we want to know to better understand this individual's experience/this social phenomenon?" and "How can we study this further?" can lead to a discussion of the advantages and shortcomings of different modes of observation, sampling issues, and matters of operationalization.

Social psychology

Concepts like reference groups, Mead's description of the stages of socialization through which a child goes in developing an increasingly complex self, are clearly germane to the scenario. Those interested in emphasizing an experimental approach might choose to substitute a reading on Social Comparison Theory, such as Festinger (1954) or Wills (1991), instead of Cooley's work, as part of the initial case. As an anonymous reviewer for this case suggested, "Social Comparison points out that we tend to protect our own self-esteem by a process called downward social comparison, i.e., comparing ourselves to people who are less fortunate, talented, etc. This case could be used to begin a discussion on how flexibly "less fortunate" can be defined. After all, people who have BIID see amputees as more fortunate because they get to show how brave and heroic they are."

Deviance/social control

In the introduction to the case, I describe briefly some of the different terms and categories that have been proposed as frameworks for understanding the desire to remove a healthy limb. From the perspective of the sociological study of deviance, what is telling is that all of these frame the phenomenon as a medical, and specifically psychological, disorder. The scenario stands as an interesting illustration of the medicalization of deviance in our post-industrial society (Conrad and Schneider 1992) and the social control functions such an attribution entails. What frameworks for deviance might be applied to this scenario other than the medical one?

Culture

Students can be asked to identify the norms and values prevalent in the larger society that are reflected in the sentiments expressed in the scenario, such as self-actualization, self-improvement, achievement, excitement, overcoming disadvantage ("Horatio Alger story"), recognition, expectations of building identity (i.e., that one's identity is something to be expressed, worked on, and its expression can be controlled), individual autonomy. How are these values similar to, or different from, the values at play in the other types of body modification in the list generated in the exercise at the outset?

Medical ethics

When is it acceptable for a doctor to perform non-medically necessary surgery? How are more common, and accepted, cosmetic surgeries similar to or different from the removal of a healthy limb? Does framing BIID as a psychiatric disorder make surgery medically necessary? In the current medical insurance environment, when should insurance companies be required to pay

for the surgery (e.g. if the condition becomes recognized as an illness and they would be willing to pay for psychoactive drugs)?* Should surgery be available only to those who, as in the case of cosmetic surgery, are able to afford it? See “Advice for Surgeons” by Robert Smith, M.D., on the Body Integrity Identity Disorder website (<http://www.biid.org/advice.php?page=06&lan=en>) for a thoughtful discussion of other considerations from a medical viewpoint.

Disability studies

Above, I discuss three points from a critical disability studies perspective regarding the view of disability portrayed in the scenario. This discussion can be extended to a more in-depth look at alternatives to the medical model of disability such as Carol Gill’s social model (see, e.g., Gill, Kewman, and Brannon 2003) and a social structural model (Engelen-Eigles 2005). From the perspective of either of these frameworks, how would one analyze the phenomenon in the scenario?

Clinical Note: Is BIID a Form of Self-Mutilation?

Regarding a connection between BIID and self-mutilation, First (2004), in a study of BIID with 52 subjects, measured the extent to which subjects’ desire for amputation was motivated by a desire for self-mutilation by asking subjects the extent to which the “the process of amputation is the main focus of desire.” Only one of the 52 subjects endorsed this assertion (First 2004:5). The literature suggests that many individuals with BIID who are intent upon realizing the amputation would prefer to have it done by a surgeon and resort to “self-inflicted amputation” when they believe a surgeon’s services are unavailable (largely an accurate belief) or their request for surgery has been denied. The literature on self-mutilation suggests a number of features that distinguish this psychological phenomenon from BIID. First, self-injury seems to be most prevalent among adolescents and young adults (Whitlock, Powers, and Eckenrode 2006; Yates 2004). Whereas First’s study suggests onset of ideation by age 16 (2004:6), his sample ranged in age from 23–77, with an average age of 48.6 years (2004:3). Individuals with BIID described in other sources cited in the References below also fit this latter profile.

Self-injurious behavior is thought to be a response to childhood trauma, particularly sexual abuse, and may be associated with other emotional disorders (Briere and Gil 1998; Yates 2004). A majority of individuals with BIID (79%) exhibit “no significant psychiatric symptoms (apart from their preoccupation with amputation) or drug or alcohol problems” (First 2004:7). According to Whitlock, Powers, and Eckenrode, “self-injury is typically a private, secretive behavior” (2006:416). While the desire to be an amputee may be private, many individuals with BIID pretend to be amputees by binding a limb or hiding it among clothing, using crutches or a wheelchair, or employing some other means so as to give the impression that he or she is an amputee (First 2004:6), thus potentially conveying publicly his or her inner sense of identity. Individuals who have succeeded in becoming amputees, depending on their choice to use prostheses and the nature of their particular amputations, may be more or less visible in public as amputees.

**The Diagnostic and Statistical Manual—IV (DSM-IV)*, the catalog of mental disorders which serves as the definitive reference for both mental health care providers and the insurance industry, does not list BIID, Amputee Identity Disorder, or Apotemnophilia. The DSM was last updated in 1994, before this condition had begun to gain attention and before the Internet had begun to provide forums where individuals could connect across geographic distances (Elliott 2000). It is currently debated whether the next edition of the DSM, due to be published in 2011, should catalog this and other relatively rare conditions at the risk of making the entire manual too unwieldy to use.

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