

**Loathed and Falling Limbs: A Sociological Exploration of  
Embodiment Troubles**

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## ABSTRACT

### Loathed and Falling Limbs: A Sociological Exploration of Embodiment Troubles

Claire Ashton

This thesis explores unique problems of embodiment with particular emphasis on the desire for radical transformations of the self by disembodiment. Based on 10 interviews with informants, major focus is paid to 4 who identify as having Body Integrity Identity Disorder (BIID: the compelling sense that one is “trapped” in their fully able embodiment as is meant to be disabled) and an interview with a leading plastic surgeon, the coordinator of psychology at a correctional institute and a professional body modifier. This permits a triangulation of different practical and ideological perspectives, often mutually conflicting. These matters can be theorized through the work of Kristeva, Baudrillard and Butler. The body is a metaphor for society and these theorists of abjection and the relations between self and society offer some insights into these embodiment troubles (e.g. the desire for amputation or paralysis).

The number of people suffering from somatoform disorders like Body Dysmorphic Disorder, BIID and Gender Identity Disorder seems to be increasing, along with the dramatic number of people accessing cosmetic surgery. These phenomena may reflect the embodiment deficit, to use Niemeyer's (2007) term: reflecting the desire for extreme physical engagements, to belong to or create a new identity, to experience a new reality, or as the transference of psycho-sexual trauma onto the limb(s) in question. The diagnosis of BIID is highly controversial: a neurological problem, perhaps, or psychological due to developmental issues, or social, facilitated by the internet. This thesis attempts to clarify this identity as meaningful to observers as it is to respondents.

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I thank my informants for their time and their trust.

This work is dedicated to Sean and Claire, whose bravery and candor made this thesis palpable. In sharing them, I hope to have done your worlds well.

- September, 2008.

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“We are what we all abhor” - Sir Thomas Browne



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## Introduction: Embodiment Troubles

Just as with so many projects we set out to write, this thesis's subject has trumped me and become something else. This transformation works as an ironic metaphorical relation with the participants in my research who have experienced the subject/object relation working against them in similarly tricky, albeit much more severe ways.

In past research I had been working through embodiment theory and exploring how authors (Ozawa 2002, Langman 2003, Wolfe 2007) were using the body as a metaphor for society, and as a site on which society has embedded its various cultural landmarks, intersecting with biology, and resulting in seemingly new bodies. This merged with my interest in epidemiology, specifically how digital technology seems to be aiding in the spreading of psycho-sexual and somatoform maladies. I was not writing about *real* medical issues, but theories of society and technology and how the body both represents and is represented by these structures in analogous ways

Through this research I encountered an article by Carl Elliott (2000) dealing with apotemnophilia, which refers to otherwise healthy people who obsessively desire to have a limb amputated. I began researching this topic and found that the material available on it is alive with burgeoning debates, ethical concerns and inconsistencies that meet such shockingly extreme phenomena. My original idea for preparing this project was to consolidate these views into a single thesis: to explore the possibilities for analysis of the fascinating

phenomenon of apparently healthy people electing to become amputees. The internet is the digital home to thousands of people claiming to suffer from this ailment, so I have combined a survey of previous research with my own interviews.

Here is where my object of research first began to show its enigmatic nature. What I was calling apotemnophilia, which was a term introduced by John Money (1977) that literally translates as 'amputee love', turned out to have several names; the variations encompassing contesting meanings and points of view. There is one camp of research headed by psychiatrist Michael First (the editor of the Diagnostic and Statistical Manual of Mental Disorders Vol-IV and pending V), who coined the term Gender Identity Disorder (GID) to describe transsexuals desiring sexual reassignment surgery. First considers the desire for voluntary amputation to be a matter of Body Integrity Identity Disorder (BIID). This term is considered useful in that it rescues the problem from the sexual paraphilia (unusual and problematic sexual desire) aspect which apotemnophilia automatically connotes (philia meaning love in the sexual sense), to encompass a more broad understanding of an overall identity problem. BIID is not a sexual disorder, it is an identity disorder. Participants are overall familiar and comfortable with the use of this term to describe their problem. The keen acceptance of the term BIID probably stems from a reservation towards indicating their desires sexual, as they are all extremely well-versed in the literature and debates and know that classification of a paraphilia prevents momentum for the potential for rights to access surgery. If enough people



demonstrate the symptoms of BIID, and if the proposition for inclusion of BIID is accepted by its editorial committee, it will receive a distinct entry in the DSM, in gaining this legitimacy, treatment options will open for exploration by stakeholders holding researchers.

Carl Elliott (2000, 2003) contests the categorical distinction between apotemnophilia and BIID, arguing that sexuality and identity are intrinsically inseparable. He implicates the increasing diagnostic categorization of new disorders in their creation, spread and psycho pharmaceutical treatment (see chapter 6). Upon initial research online I came across approximately one hundred websites host to a specific vocabulary for people obsessed with disability (usually amputation): the website run by one of my informants, "Sean" is unique in that it opts for the term *transabled*, as a sort of politically correct alternative to the following; online there are thousands of *wannabes*, these are considered the people with apotemnophilia or BIID who are aroused by the idea of being disabled. *Devotees* are fascinated with their sex partners being amputees (or another disability), and *pretenders*, who are likely *wannabes*, literally pretend to be disabled. *Wannabes* may also be *devotees*, and possibility *pretenders*. For all groups, sexual arousal is considered contingent on the fantasy of disability.

The splintering of radical embodiment troubles of this order into several specific categorical directions was a confusing and revealing aspect in beginning to research this paper. I began re-thinking the groups I had defined and decided to focus the project on radical transformations of embodiment as demonstrated

through voluntary amputations, among other forms of problematic discords between our body as we conceptualize its ideal form and the form of our physical embodiment as it presently is. I re-named the project (Loathed and Falling Limbs: A Sociology of Elective Self-Amputation) the more inclusive title; Loathed and Falling Limbs: Extreme Embodiment Troubles.

There are a variety of disorders that can be included under the umbrella term "Embodiment Troubles" including those problems recognized by First and other therapists as related to, but distinct from BIID, including Body Dysmorphic Disorder (BDD). BDD sufferers are characterized by their exaggerated perception of a physical flaw which may appear in a very mild form, but is inflated by the person experiencing it to the point at which it controls every facet of their life. Often BDD patients are unable to keep jobs, relationships or even leave the house. They are severely self-conscious and spend their time consistently obsessing over the problematic feature of their embodiment. In some cases the obsession may prove fatal; an example of BDD as told by my informant Dr.

Schwarz:

*"I'll give you an example of a type of dysmorphic syndrome which is not only serious; it requires treatment, but is also dangerous for the doctor, I don't know whether you're aware of the acronym SIMON; single, immature, male, obsessive, narcissistic. These are typically young males that are obsessed with their nose, it's a dysmorphic syndrome, and they're so obsessed that they're operated and they're unhappy regardless of what has been done and they often turn violent towards the physician, there have been 3 or 4 cases in North America of plastic surgeons that were attacked, a couple of deaths. One in Montreal, an older plastic surgeon at the Royal Vic, who was attacked with a steel pipe as he was coming out of his office by one of these patients. They're loaded with hostility behind all of the other things I have mentioned to you. So they're ill people and if you don't recognize it... I operated on one of them and regretted it forever.*

*He's fine, often they're quite bright, but they'll never be happy. They'll never be happy. He had a perfect result after the rhinoplasty, but he went and got someone else in the States to put a bone graft in his nose after that!"*

While Dr. Schwarz, among others, may consider Body Integrity Identity Disorder a form of Body Dysmorphic Disorder, others (namely First) value its purported uniqueness. Just as BDD researches have successfully asserted its distinction from OCD (Phillips, 1996), BIID removes itself into further categorization as distinctive from BDD under the somewhat hazy diagnostic criteria as laid out by a team of researchers at the 3<sup>rd</sup> annual BIID conference (First, 2003), which surmises that BIID sufferers perceive their embodiment as normal but foreign, with an onset occurring in childhood, but is always established after puberty. BDD is importantly distinct because it does not occur until adolescence.

This timeline does ally with my research participants who identify the period between adolescence and early adulthood as the time in which their desire came out *in full force*, though it seems logical that the establishment of BIID immediately following or during puberty would necessarily comprehend an element of sexuality that can only be realized as physical desire and sexual identity are becoming increasingly fortified by the embodiment's changing form. BIID advocates insist that there is no sexual element for some sufferers. Some of my interview participants are adamant about this distinction, while others express some confusion. For example, while Sean reveals that he does have a "slight bondage fetish", he feels that this does not necessarily relate to his desire for immobility (to be a paraplegic) and while he asserts that (in relation to his

sexuality, sex drive, etc...) that he is "*fine there*", "*all normal*", he would not mind genital dysfunction (impotence) as a consequence of his paraplegia. Perhaps this division is an essential component of the rhetoric surrounding the categorization of a new illness experience for both the physician and the patient, forbidding its inclusion in the paradigm of another paraphilia, and increasing its eligibility for legitimacy and treatment through surgery.

BDD is an example of a Psychosomatic or Somatoform disorder qualified by the experience of physical symptoms for a condition which is not (yet locatable as) physically present (other examples include hysterical blindness and chronic fatigue). A recent study by Ramachandran and McGeoch (2007) searches for links between BIID and *somatoparaphrenia*:

*"A condition which can occur after a stroke in the right parietal region, (where) the patient denies ownership of a limb on the left side of his body—typically the arm... We propose that BIID is caused by an uncoupling of the genetically based scaffolding of one's body image, in the right parietal region, from the actual physical body parts that this area normally represents. The fact that most BIID patients date their symptoms back to early childhood would be in keeping with a genetic basis for this uncoupling."*

Their research involves stimulating the right parietal region of the brain by shooting water or air into the ear. One of my participants, Claire, also participated in this study and found that she experienced "*no changes whatsoever*" aside from her initial bout of sickness and confusion immediately following the procedure. The study did not report any significant findings. They are now looking at brain scans of participants identifying as having BIID and hoping to discover more concrete findings. The sample they are currently working with on

the more recent portion of their research numbers only 4, and although they inform my participant Claire that they have discovered that the body imaging area as somewhat smaller in these people, the sample is hardly reportable.

While some experiencing BIID retain hope that there may be a locatable neurological basis for this disorder, others insist that it is past due time that surgery (amputations or spinal cord dissection-to cause quadro or para paralysis) becomes a viable option. Thinking philosophically about the experience of BIID provokes another possibility for the answer to this particular mystery- that there will be no cure, (only treatment through the achieved solution of the person suffering via surgery, pretending, or another means) because it is a culturally influenced psychological disorder. People feeling the effects are not illegitimately doing so, but the disorder is likely one that does not have a particular genetic origin, as the lack of findings in the Ramachandran study suggest.

All participants indicate that they have self-injured on one or more occasions but are not chronic self-injurers with the exception of the prison population. Most people who opt for a single major embodiment modification such as amputation or partial paralysis differ from chronic self-injurers in that they may self-injure once or twice in an attempt to inflict severe enough damage to remedy their embodiment crisis, but they do not repeatedly or demonstrably inflict injuries to punish, harm, control or save themselves as do self-mutilators (Favazza, 1987). Self-injury is discussed at length in chapter four.

A part of the reason BIID is frequently drawn parallel to GID is that the researcher of both phenomena is the same person (First). Through an overview of the literature and in speaking with patients it seems that BIID has more in common with GID (which is categorized in the DSM as a sexual disorder/dysfunction) than a somatoform disorder such as BDD because of the particular language used when expressing the illness experience. A major commonality between BIID and GID lies in the way patients explain their identity disconnect. There have been no marked neurological effects which support that either is a psycho neurological problem, but there is very strong qualitative evidence that this is not simply a condition created by its sufferer's either.

It is important to note that body modification practitioners do not usually identify themselves as suffering from BIID, and there are very significant differences between the groups, however there are also some commonalities which have emerged in my interviews. One of these common threads is the compatibility of the psychoanalytic mode of analysis to the embodiment experience of the sufferer. Another shared thread is the desire for new tactile or sensational experiences as a principle motivator for the (dis)embodiment experience (e.g.; phantom sensations) and a related hedonistic drive (or that resignation from hedonism as we would traditionally regard it through paralysis or amputation).

This project will provide an exploration of some extreme embodiment troubles and highlight theoretical debates that surround them in discussing the works of Kristeva, Baudrillard and Butler as they pertain to the identity of the

contemporary subject. I will focus on the role of the internet, pretending, self-injury and language as these themes relate to the illness experience of BIID sufferers and others who (desire to) inflict self-harm and explore these themes through a psychoanalytic lens. This will serve as the first comprehensive analysis of BIID within the discipline of sociology.

**(Introjection):**

After breaking a bone my foot was set in a plaster cast, which was burdensome and lumbering in addition to it being difficult to maneuver with crutches. I found it too hard to walk much and became reclusive, exhausted and not feeling up to socializing. One night it began to feel as if my foot and leg were swelling rapidly- trapped in the cast. I felt the circulation cutting out and a burning tight sensation making it frustrated yet numb. I was sweating and anxious. I did not tell anyone what I felt was happening to me, because I knew none of this was *really* happening; that it was a combination of intoxication- a few drinks on top of the pain medication- and my discomfort and reduction of mobility that was contributing to the feelings of panic and entrapment. Still, my panic rose. What if it had grown to the point at which I could no longer keep at bay the hysteria that was creeping into my thoughts? If I had logged online and found a 'broken foot community' blog and read that there were many others who suffered this feeling, that it lasted for almost everyone throughout the whole duration of their casting, and for many the rest of their lives (or at least long after the cast was removed); would I have dismissed these fellow sufferers as crazy? Would the fear that I would become 'crazy too' move me to remove the cast then and there? What if I

persisted to participate in this online identification and began to consider my hallucination a reality, one more common, more normal than I had ever imagined? What if I continued logging onto the website and the pain got worse: I found other forums and spent hours a day discussing my podiatric suffocation? It could become the focus of my life, and because it was the focus of my life, I could no longer stand to have the cast removed; who would I be without it? Let's say, in perfect irony that the cast became my crutch. I realized I suffered from a mental disorder and began advocating for treatment options; drugs, injections that temporarily paralyzed or killed off the nerves below my knee, amputation of the foot-anything to free me from my suffering, and simultaneously legitimize my identity. If I had known this was the alternative option would I have cut off my cast as soon as I realized this was a real problem, and forfeited my bones best recovery? If I had, I would have never known there were others who could share in my disability- that I was not alone, that I was not crazy, that I was part of a group for whom this was *really happening*.

This may sound like an insane scenario, and of course only part of this story is true: I did feel trapped and panicked in a cast, and I quickly sobered and acknowledged that I was merely imagining, attributing my stress, hallucinating. I did not turn to the internet and amass a community of like sufferers in which to belong, but I do believe in the possibility for some people facing embodiment troubles to somehow find themselves in this disposition; to have had a fundamental experience with a person who has a disability and incorporate this into their developing psychology. This may lead them to medicalize their



emotions, their paranoia, their loneliness; to find company and simultaneously set themselves on a trajectory that seeks a radical, final solution. What else possesses the unprecedented power to amass, to network, to influence, than the internet? In reality many people find themselves in very dire and much more extreme versions of this tale. My informants' stories, their obsessive desires, their *need* for radical body modifications of their physically healthy bodies, like amputation and paralysis are the reason for this project. What makes them even more compelling is their insistence that their identity confusion is real and can be traced back as far as youth.

## **Methodological Considerations:**

To date, there has not been a long-format sociological project dealing specifically with those who suffer BIID, or those who undertake more radical forms of body modification such as amputation. The internet provides numerous forums for such people to engage in the philosophical/sociological conversations coloring their situations, and this thesis attempts to highlight some of the themes emerging through these discussions and work as an inclusive theoretical frame through which to begin interrogating like embodiment troubles.

## **Sample Recruitment:**

Participants in this research project were recruited either through mutual contacts, or by posting on message boards of a web-forum for people desiring a body modification (in the form of an amputation) or identifying as having Body Integrity Identity Disorder (BIID). The webmasters of two of such sites contacted me via e-mail and became participants in this research. Respondents were either contacted by e-mail or telephone to organize a meeting. The conversations lasted approximately two hours and proceeded through a series of emails, or meeting face-to-face. Identities were camouflaged by participants from the beginning, and any personally distinguishing information was disguised without compromising the accuracy or quality of the participant's statements. All participants were given the option to disclose their actual identity both to myself

and the readers of my paper, but only those who did not desire radical modifications of embodiment opted for this type of disclosure. This includes my 'professional' interview subjects; a psychologist at a multi-level security corrections center, a practicing member of the Royal College of Physicians and Surgeons (plastics) and a body modifier who works in a professional studio setting.

The total number of research participants for this project is 9, with the majority of focus surrounding conversations with the 4 main participants who identifying as having BIID or otherwise desiring a radical modification of embodiment.

#### **Characteristics of the Sample:**

Due to the troubled nature of this topic, three of my five central participants had already crafted precise concealment techniques for discussing themselves. As participants in online forums they use pseudonyms and are very careful not to reveal their specific locale, official job title or familial characteristics. They were still very willing to disclose their ages, the general region they inhabit and the basic quality of their careers, as one participant stated;

*"Sean O'Connor is a pseudonym. I am extremely cautious of my real identity, particularly as I've lived for nearly 12 years as a full time wheelchair user. Friends and colleagues know me as disabled, and if it came out that I'm not indeed disabled, the shit could hit the proverbial fan. Too much of a risk, not divulging that...In any case, as it is a pseudonym, you can, and I encourage you to use it. I have nothing to really hide. I have spoken enough and completely candidly about this on my blog. I change some details that would be too easy to identify me, but not that many."*

The following tables express the basic demographics of the participants:

**Central participants:**

<b>Name</b>	<b>Age</b>	<b>Gender</b>	<b>Country of Residence</b>	<b>Desired / Achieved Disability</b>	<b>Occupation</b>	<b>Relationship Status/ Sexual Orientation /Children</b>
Claire	Late 30's	female	Canada	(pretender)  Desires paralysis of legs	computers	married  heterosexual  3 children
Martin	34	male	USA	Has knee fusion	professional	Homosexual  no children
Tobias	30's	male	Denmark	Desires left leg, above knee amputation	computers	has partner  homosexual  no children
Sean	40's	male	New Zealand	(pretender)  Desires paraplegia	Computer programmer	Heterosexual  has partner  No children

**Additional interviews:**

Male in mid-20's	Lives in Canada	Conducts extreme modification surgeries
Male in mid-20's	Lives in Canada	Family has history of self-injurious behavior

**Professional Participants:**

<b>Name</b>	<b>Expertise</b>	<b>Country of Residence</b>
Adam*	Body modifier, works in studio and is heavily modified	Canada
Jeff	Coordinator of Psychology at Springhill penitentiary	Canada
Dr. Gaston Schwarz	Plastic Surgeon, professor at McGill medical school	Canada

\*While Adam does not identify as having BIID, he is heavily modified and represents the body modification sub-group

Among my central interview participants, Martin has a DIY knee fusion (arthrodesis; the fusion of the femur and tibia which renders the knee immobile),

achieved through 8 years of living with a brace on his right knee, Claire and Sean desire to become paraplegics and live as “pretenders” spending much of their time in wheelchairs. Tobias desires an above the left knee amputation and plans to have one in the near future, Adam has had both of his earlobes removed, an ear bisected, numerous implants, piercings, tattoos and scarifications. He plans to amputate one of his digits. All except Adam identify themselves as suffering from BIID.

The clinical or otherwise professional participants include Dr. Gaston Schwarz, a practicing fellow of The Royal College of Physicians and Surgeons of Canada (plastics), Adam who, as well as being heavily modified, works as a body modification artist, and Jeff Earl, the psychology coordinator at a mixed security correctional institution. I have found that the expert analysis from the various professionals has enriched my understanding of the patient-clinician rhetoric above all else, additionally this somewhat rounded inventory of experts has served to improve my interview capabilities.

Throughout this thesis, and particularly in chapter 2, I draw on the autoethnographic approach using my own life-course experiences, and, more recently, my experiences with the plastic surgery system, having had the first surgery of a series of scar revisions (the result of a dog attack in July of 2007). I have been through the rounds of speaking with 6 different surgeons, all but one on multiple occasions, and have notably observed our interactions, making for an incredibly useful first-person experience with the workings of this type of medical system. I have read the transcripts of 12 interviews from broadcast (Soundprint,

2002) and televised (BBC, 2000) documentaries conducted by other researchers, and though I do not address them specifically they have been a valuable resource simply in observing their compatibility with my own findings.

**Procedure:**

I originally identified five groups who desired amputation, based on the literature and my own internet research into discussion forums and websites. I considered the population to include groups of those who one would call fetishists – those with an overtly sexually desire to be or to have sexual relations with an amputee (otherwise known as apotemnophilia), those people who suffered from a single seemingly random ‘need’ to become an amputee to match their ‘true’ identity (BIID), some people heavily into Body Modification practices (tattooing, scarification, suspension, etc...) where the amputation is typically more minor (fingers, toes) and is predominately described as an aesthetic choice, rather than a total and encompassing obsession. There are also chronic self-injurers who eventually amputate; those who often haunt the corridors of mental institutions and disrupt the usual disorder of prisons, at times through a castration or other form of body modification. These voluntary amputees are typically slotted into the category of self-mutilator, and are often diagnosed as psychotic or delusional, still the extremity of their mutilation deserves closer and more specific examination. There are also examples of elective self-amputation to save oneself from literal entrapment (for example, in the case of a mountain climber trapped under a boulder) or that performed to solicit insurance (for example, a worker who ‘looses’ a finger on the job and receives various forms of

compensation), but these groups do not correspond thematically with my research.



Image of a scarification done by Adam

Whereas I had envisioned my thesis as a survey of the groups who desire voluntary amputation, I quickly discovered while requesting interview subjects by posting on discussion forums specifically speaking about amputation, that there were other forms of these imagined bodies. My first correspondence with Claire included the following statement:

*“Unfortunately you've written to the wrong person, as I don't desire an amputation. I desire to be a paraplegic. There is rampant, widespread misunderstanding about BIID on many levels, but one of the misunderstandings is that it's all about amputation. There are many, MANY people in the BIID community who desire paralysis, and to a lesser extent people who desire blindness or deafness. Unfortunately the media chooses to focus strictly on the amputation issue - probably because it's more shocking and graphic and more sensational value for them. But, as with most things, the reality is much different than the media would have you believe. I hope this doesn't come off as harsh. You find me very*



*unhappy with people doing studies and reports on BIID of late. I have been burned, and wasted MUCH time with people wanting to study or report on BIID who ultimately paint a sensationalist, negative and/or inaccurate picture of it”.*

After reevaluating my direction I decided against specifically soliciting a representative for each of my previously defined groups. Instead, I chose to conduct open-ended semi-structured interviews with individuals who suffer different forms of BIID, as well as others who have body modifications on the extreme spectrum. The interviews often had the informant draw on evocative memories of their development of identity and sexuality. I very much appreciate emotional responses and was not looking for specific data. This provided a particular challenge when analyzing the responses I had gathered as an aggregate. Because the interviews were so open I did not necessarily ask all of the respondents the same questions. This was important for the natural flow of conversation, and it allowed themes as well as specific and parallel experiences to emerge through our dialogue.

It is important to me that participants understand that their participation makes the research a cooperative process and that their individual voices emerge through the narrative we create. It is because of this partnership that I very much prefer interviews to be conducted in person. I must admit, however, that I did not find the interviews I conducted in person to be necessarily richer than those articulated via e-mail. The overall openness of participants and the quality of their responses were not hindered by the form our communication took.

This came as a bit of surprise, but then, anonymity is often a catalyst for most honestly expressing oneself.

The interviews were conducted throughout the spring of 2008. They focused around both the practical components of the participants experience with their specific embodiment troubles as well as the theoretical insights they offered into their personal experience, and the experiences of others suffering from similar experiences. I discovered that BIID sufferers are an outspoken yet officially silenced group. What I mean by this is, although their voices remain largely within the margins (the majority of people, including therapists and physicians have never encountered their specific problems), or are relegated to the digital realm (internet discussion forums) they are strongly versed on the issues surrounding their predicament, have formulated firm opinions and are staunch advocates for their "disability's" recognition and treatment. Of course my informants are advocates, and we must consider that there are more suffering from BIID who would not come forth to participate in my research, or be quoted in a *Newsweek* article (Sean) or participate in the research of Ramachandran and McGeoch (Claire). This does not serve as a substantial limitation in my opinion, as their position as de-facto leaders has enabled them to speak with hundreds upon hundreds of other sufferers as well as inform their knowledge with all of the available sources. On at least three occasions I was recommended academic readings to enrich my understanding of the issues by research participants. This was a necessarily humbling experience and made the research experience a more genuine exploration for me.

Interviewing these participants was a truly invaluable experience both on a personal and professional level. Their probing intellect, sense of humor, and willingness to self-reflect made the research process a journey of mutual self-discovery. The apparent absurdity of BIID was not lost on participants who empathized with my confused and at times misdirected questions; they were empathetic and helpful and truly made this research a collaboration. On several occasions Claire and Sean expressed dismay with the way their words had been usurped in the past by researchers and journalists who present an inaccurate portrait of BIID and my hope for this project was to represent them as fairly and accurately as possible without compromising the critical nature of the inquiry I intend to craft.

I feel that if this goal was realized it was in part because of my ability to interrogate my own experience of embodiment troubles and however different, parallel them in some sense to the experiences of my participants.

**Limitations:**

Due to my small number of participants I cannot begin to purport a representative sample. I still believe that this research is valuable, not only in its innovation, but for the quality of conversation this minimal sample has allowed. Interview participants were truly candid and qualitatively expressive; this has led to rich content which aids in the avoidance of generalizations. As my research was primarily motivated by an absence of bodies in embodiment theory, and the application of contemporary theory to specific real-world examples of seemingly

new embodiment troubles, I do not consider the inclusion of such a small number of individuals problematic. I had access to a plethora of other interview scripts with like participants and did observe congruencies which supported my research themes. However, because I approached my interviews and their analysis as specific case studies of informants, I did not find it particularly helpful to draw on specific examples from these alternative interview scripts.

This project is partially structured by a psychoanalytic framework, which works as a limitation because informants were often asked to draw on their memories to answer questions. I doubt very much that this is any more of a limitation than the interview model in origin, it is always nearly impossible to discern fact from fiction, but this is what makes for charmingly enigmatic research.

This project is very much an exploratory study which provides an overview of these kinds of embodiment troubles and highlights some of the philosophical debates that surround them. It is also an exploration of theory- of using the writing of Kristeva, Baudrillard and Butler and the insights they provide to both explain and be challenged by the phenomena I discuss. This is the first long-format analysis of BIID, and a first within the discipline of sociology.

## II

### **My Embodiment Trouble:**

I have certainly experienced all of the usual hurdles in finishing this project, and some less than usual. As I sit here pondering this thesis, looking back on the quickly dissolving semesters behind, I now see that my struggle has proven to be one of my most compelling research resources. You see, in July of 2007, I was attacked by a standard breed poodle, and the result was a rather intense trip to the ER and a disfigured upper lip and moderate keloid scar. Since, the scar has healed quite well and I have had the first of a series of surgeries to revise the lip.

The event was a quite literal enacting of a traumatic climax within Kristeva's *Powers of Horror* and often reminds me of that patient of Freud's, Little Hans (whom Kristeva also discusses), who fears the horse, and in particular, the horse's mouth. Though for Freud Hans's fear is manifest of his inarticulable castration anxiety, and for Kristeva it is the symbolic power of the object of phobic desire, a "*hieroglyph that condenses all fears*" (Kristeva, 34), my experience saw no original symbolic interaction, but the very real fleshy intersection of subject and (beast) object through which the loathed object (the dog), emerging from this sadistic canine experience, became encompassed by my disfigured lip itself. I, in some sense and for some time, became a living metaphor for that disfigurement that was my lip. Likewise, my informants who suffer BIID, apotemnophilia, BDD, or whichever signifier you select, are so wholly

consumed with the body *part* in question that this part becomes not only the object of desire, the desire to destroy that loathed appendage usurps a healthy subjectivity for the person in question. Their limb or the desired form for their body, becomes the universe of their experience. After the attack my initial reaction was of that savior shock, which prevents the trauma from loading the foreground of our thoughts. Later, repeated intrusive thoughts of dog attacks and specifically of the dog mouth biting occupied much of the life of my mind. To speak in the language of Kristeva or of Lacan before her, the subject confronted with the Object (other) also confronts the other (his ego) or "*objet petit a*": the abject.

The specifics of my injury and the trauma of its occurrence are not necessarily what motivates my desire to better understand the complex relations my informants are going through, both within their own psychology and in society. Rather, my new found presence in the community of those whose primary concern is aesthetic enhancement (I had at least two appointments with six different plastic surgeons before deciding on one, as well as assessments with general practitioners and therapists), and, moreover my newly minted belonging in a body (a face) that was foreign to my developed schema of *what I look like*, that was quite profound. The experience of a separation between the body as an imagined whole and its fragmented parts is an essential component of the infant's development of the ego. Alienation results when *what one is* and *what one desires their physical image to reflect* are discordant. Through my accident I was able to interpret the feeling of discomfort with one's own body

from a subjective perspective, one which was not the experience of the usual embodiment woes (loose weight, hate nose, etc...), in that it included involvement with facets of the medical system in which most of my informants are well-versed.

There were also, of course, some very large and essential differences; I do not connote to have shared an experience with any of my participants. To begin, all of our experiences can only ever share particular ideas and factors, and are very much subjective. My problem was an unwanted injury and the resulting trauma and treatment, I doubt nearly as complex an embodiment difficulty suffering BIID. I was also able to easily access surgery to 'fix' my problem, a surgery that is covered by Medicare when performed in a public hospital. I was able to skip on the scrutiny with which some doctors evaluate their patients eligibility for plastic surgery. I was seen as a victim of one of life's unfortunate twists and every doctor I spoke with was kind, sensitive and willing to be very accommodating. This has not been the situation for my informants, something I already know through research. I gain insights into this fact through my conversation with Dr. Schwarz, and through an exchange I share with Sean over e-mail in which I discuss my injury and treatment:

*"Every time I hear something about such surgeries, I think to myself that it's quite unfair. Surgery to improve a scar left by a dog bite is, arguably, merely an aesthetic thing. Obviously, some dog bites leave faces and body ravaged and surgery can fix that, but in general, such bites don't result in lasting emotional ill-being...I'll admit to envy. One simple 20 minute procedure would take care of 35 plus years of emotional agony. Heck, one injection of phenol in my spinal cord would be even faster than 20 minutes, and less costly than a spinal cord transection. But that is denied to me. And so I envy those who can get plastic surgery to fix*

*scars, or to enlarge breasts, or to suck fat out...I am angered, enraged, at the medical community”.*

I agree with Sean to some extent. Of course embodiment troubles are subjective experiences and we can never really know precisely how someone else experiences them, but I can imagine how what I felt could be elevated to extreme proportions. At the same time I am amused by the tendency for most of my informants to identify others' embodiment troubles as somehow more socially or psychologically problematic than their own: that the desire for cosmetic surgery reflects a sick, twisted social ideal. This is articulated in the following passage from my conversation with Adam;

*“We live in a really, really sick society. I mean the sick cannot be treated and people are sick because their bodies aren't the way they need them, or they're not the way they should be, or they feel they should be. And they are not being treated, and the people who are being treated are eighteen year olds getting nose jobs, because they want to look like the girl on the cover of a magazine. I mean, that's where the sickness is, and their parents should be prosecuted, they're the ones, for not bringing up their children right. I mean, not those who have a dissociation with their body parts.”*

When Adam sympathizes with people who have “*dissociation with their body parts*”, he is referring to people who feel the need to elect to become amputees. Adam and Sean both cast judgment on the system of conventional plastic surgery, which allows candidates to make what they consider aesthetic choices governed by unrealistic social standards for beauty, that these forms of desire for transformation are of less conviction than someone who feels the need to match their body to their mind in an unconventional manner through radical,



unsanctioned body modification. I feel that Sean is putting me into this category and my resistance to that order forces the realization that I too am judging these plastic surgery clients as somehow less worthy than myself. This is a consideration I continue to ponder as I prepare for my next operation in September. I wonder how many procedures it will entail until my lip is rendered as close to pre-injury as possible- until it is no longer officially 'deformed', and whether more surgeries transfer my status from reconstructive to cosmetic. As often as I ponder the ethics of plastic surgery, I am not exempt from being caught up in the kind of rhetoric that values a hierarchy of acceptability and necessity for plastic surgeries . I reply to Sean, "*I know my desire to have my lip returned as much as possible to its natural state is far less significant or debilitating than your desire to become paralyzed*". He responds:

*"But what would it have become, if left unaddressed for 35+ years, decades where you needed to have your lip "fixed", and where surgeons weren't willing to help? Would/could it have grown to the point where you could not endure it, or yourself, anymore? Rhetorical question, obviously, but one worth considering."*

This prompts me to remember that over the past year almost every time someone would ask me about my lip I would tell them I was to be operated on, subtly assuring them that I would look better, *don't worry about me, I won't always look this way*. My response was also motivated by hope that I would eventually look better, knowing that logic dictated that I would, that this glaring little mound that drew so much attention would be remedied. This belief kept me together through all the horrible encounters and penetrating stares. I cannot count how many times I thought; *no one around me knows exactly how this feels*.

When I look back on my writing I am taken aback by the darkness of that psychological space from which I have finally emerged. Had I not had this pretty facile experience with accessing surgery once the wait was over, what would my story now be? Would my embodiment trouble have become a complete obsession akin to that of Sean or Tobias? In my interview with Dr. Schwarz I tell him about the sense of injustice that pervades my informants opinion of the plastic surgery field, that they feel tremendous frustration that comes from feeling like they should not only be permitted to do something, but that they are a more valid candidate than the people who are free to do it. He responds:

*"I can fully understand and sympathize their frustration at the of lack of attention from our specialty, perhaps, simply because it is a very complicated issue, it's not simple at all. Today we live in a society that is fast and super specialized. So, nobody wants to take the time to listen to these people and their serious concerns... and their problems are labor intensive. So you say, you just go to a clinic that deals with their problem... and I recognize it. I recognize that it's our fault to some extent, making them frustrated. In other words we recognize that it's a serious problem, it takes an awfully long time to deal with these patients, so, you know, you let them be handled by experts who are more interested in the problem".*

I imagine that Sean and others would be even more frustrated if they knew that Schwarz considers their problem one of BDD, and does not recognize what appears to be their primary goal, that is, the validation of BIID as a 'real disability' (and the choices that might stem from that recognition). Still, Schwarz's empathy comes as somewhat of a surprise to me. I am accustomed to "transabled" people dictating stories of clinicians being shocked, rude, dismissive, repulsed and impossible to negotiate with. For most people, accessing cosmetic or

reconstructive surgery it is a simple task. I do not intend to underpay the ethics of surgeons, which vary from physician to physician, but where large sums of money are involved a little doctor shopping may be all that is required to access any operation. In my situation, I did not have to go to any lengths to conceal my motivation for surgery, or to say precise things to camouflage the extent of an obsession. I was looked at as a different type of patient and I was treated a little differently. There were looks of sympathy and overt kindness. Receptionists chatted with me a little longer and a general sense of *poor girl in an unfortunate circumstance* was the overall feel.

My experience in the streets of everyday life lacked whatever reserve or sympathy I was treated to within waiting room walls. I was completely stunned by the number of people who would approach me, sometimes on a daily basis, and ask me what had happened to my lip. I still wonder how they could be so blunt as to interrogate me without knowing whether my appearance was one I had since birth, or one that would ever be altered. On two separate occasions I was even subject to a complete stranger approaching me and touching my lip. I frequently wondered if people with major disfigurements had to deal with the same kind of intrusive attention I was becoming so accustomed to. I was beginning to understand how unsettling it was to be in a foreign form, to empathize with what it might feel like to look, simply put, 'as you shouldn't'. I felt as though my face, my identity, was wrenched from me and this became, temporarily, all that mattered to me. When that small portion of my face was changed my body image as it had always been imagined was changed. On the other hand, I was aghast

at how anyone with a normal embodiment could ever want their body to become disabled, to make the conscious choice to become disabled or disfigured, if only because of the visibility, the stares, the questions. Or was this the seed of their motivation? Perhaps it was because my disfigurement was mild that people felt it was easy enough to approach me about it. Perhaps people in wheelchairs or amputees are privy to a sort of unspoken and constant observation that I imagine is far worse.

The period of adjustment to the new way I looked was tedious and is ongoing. I now look different than I did before, and after the attack, and after six months waiting for surgery, and after the first surgery. I look different than I will after the next operation. This ebbing, (however subtle in my case) process at least gives me points of reflection and marked observation that are demonstrative of the embodiment trouble experience.

### III

#### **Embodiment Troubles, Self Injury:**

I remember when I was in junior high school on the cusp of Kurt Cobain's suicide (which was a profound pop-cultural landmark for many of my generation), there was a cutting trend. These cuts did not present very serious danger, they were all superficial wounds, but there was a coolness (now, how profoundly regrettable) that a thin red streak along the inside of the wrist could elicit that was unmatched. Ever since this formulative experience, I have always been fascinated by the phenomenon of self-harm, the marking of a trend, of hating oneself, of fitting into an identity (or whatever else it may be), onto the flesh. I wonder about the stimulus: is it pain or release, adrenaline or desperation? What are the possible mingling qualities that provoke the act of cutting, and where and when do they finally end? While I consider cutting the body, body modifications (as part of the body modification subculture), and people with BIID or apotemnophilia all different phenomena in many important ways, their mutual self-injury and physical transformation may be qualified by the term embodiment troubles.

Over the past few years my interest in this sort of ritualistic marking of the flesh was again refreshed. While backpacking through Bolgatanga in the northwestern region of Ghana just south of Burkina Faso, my travel companion, Kelly, and I stay the night with a family whose son we had met at the market. Okino's family live in a rat infested ghetto, and although our room is cozy and

neat, the sound of fat rats sliding around the patch tin roof all night was enough to keep us from sleeping at all. The following night we opt for a hostel, but we still spent time with the family, and their children became our tour guides for the remaining few days. One of these children, Sara, knows some English and is a kind and gentle spirit. We share looks over our very suave new friend Okino and this expedites our friendship. Sarah brings Kelly and I over to her house so that she can braid Kelly's hair, and on that day we met Sara's baby and realize that although we considered her a little girl, she is a woman in some very critical ways. Sara is only 15, but has the care of her own 6-month-old daughter to attend to. While I know Sara loves her child, she does not seem ready to be a mother. She passes off the baby at any chance she is given and seems frightened and daunted by her presence. When it is time to feed the child she pulls down her top and her tiny breast is covered by a lace bra. I ask her about it and she says that it is a gift from the baby's father. I ask her where the baby's father is and she shrugs. For the hours she is braiding Kelly's hair I take her baby, play with her, hold her and my much heartier frame is tired and I want to rest. I feel badly now for thinking that she was passing off the child so easily.

While I had become accustomed to the rituals of scarring in Ghana: the common tribal distinction shared by most of its population is a hook shaped scar underneath the eye on one or both cheekbones, I notice markings on Sara's baby that are quite different. Around the baby's neck, wrists and ankles are dozens of small slash scars, about one inch in length and thin as a razorblade. Most appear to be months old, but some are newer. I ask Sara why her child is

cut up so badly and she replies that she had been sick with a very bad fever so they carved her up to let out bad blood. Panicked, I try to explain to Sara that she needs to take her baby to the government hospital whenever she gets sick and that bloodletting is not a cure that works. I try to show her how a baby does not have as much blood to loose and that it causes a lot of unnecessary pain for her little body. I plead her understanding and am visibly worried. She says that she knows it is not good, but that she must listen to those who take care of her, and she shrugs her shoulders.

I am upset but not naïve. I have been working in this country for months with HIV positive patients, some the most far-gone and unhealthy people I have ever seen. They come to the hospital without a shot at ever surviving longer than a few months: man and woman leaving farm and family of fifteen to bring their barely incased bones to a test that will only verify what we can all already see. I now know how to look at someone and know they are well into a battle with AIDS: there is a sallow expression that is not like any other hollow cheeks, there is the glaze in the eyes. It is as though their skeleton has become a vacuum, sucking all flesh into a pit of nothing. Ever count the teeth of someone unable to muster a grin? I think, this is a land (in many ways) of suffering. A suffering different from our own, void somehow of our lonely melancholia- that which feeds hordes of new mood disorders and somatoform disabilities- but one that is profoundly burdened by a legacy of endless struggle. Of all this, there is something about those abject limbs of Sara's little girl that shake me right down deep. It was the best laid plan, the making of a better life, the intention that was

so misplaced. There I was, the animated Obruni (colloquial expression for white person which translates loosely to 'on the horizon', as in ships on the horizon which were the first signs of whites coming to the Gold Coast to initiate the African slave trade), sprung alive by the struggle to explain infection and antibiotics to fifteen year old Sara, hips so skinny it was a wonder she didn't crack in two when she brought this fat and now healthy, scarred and grinning life into the world. Sara in the rat ghetto. Sara who Okoni told me that she works as a prostitute. Sara who was doing what any young woman put upon by a world that did not care for her might do to survive, to fill her hungry daughter's stomach. I want to take their scars and make them disappear. They are beginning to look like shackles on this dear baby's wrists and ankles. I am urgent and want to make Sara understand that her intuition was and will be right; that she needs to do what she knows is right because it is her child, but I am an ironic, laughable thing on the horizon trying desperately to import my knowing, even though I see that our ways are not helping, they are afraid of touching, they are not healing. Our ways are talking to the rich Blacks at the Universities and making ethnographies about it. I am enraged, but I suddenly want only to crumple and disappear. I am exhausted and within a few days malaria's heavy sick fog will have hung itself over my bones and I will feel justified to sink into myself, that just resolve of the illness experience. But right now I want only to tell her in a language she might understand- *please, please, bend, but do not break to the thin and endless sting of your struggle.*



I move to Montreal and meet a new friend who has carved his arms over the past four years into birch tree branches. Smooth white scars circling round and round. New cuts are red and freshly bleeding. His is one of the most extreme cases of self-injury I have witnessed. He says the pain makes him pass out so that he can fall asleep. A year later he tells me that his mother also chronically cut herself and eventually killed herself and that his grandfather cut off one of his fingers; *"It was after the German occupation of Alsace during World War II and he said 'the Nazi's made me to it' "*. He makes me wonder whether there is a biological determinant to this type of psychological or identity problem. His is certainly not the only case of morbidity. My cousin is working at a group home in Ottawa where every single female resident is a "cutter". Razors and knives are not allowed. She tells me about one time when she was in training, someone shouted to her to bring towels and when she entered the room she saw one of the girls lying in a pool of blood. She had likely not meant to, but had gone fatally far.

On a spring break trip to Mexico I discover that my friend and bunkmate has scars covering his stomach and chest. He sees me looking at them while we swim, but I do not ask him why and he does not tell me. So, it is psychological, cultural, social, it may be biological. It seems that they are all letting something out, some sickness, and wearing the signs.

Through all of this I remember Sara's little girl. I have several photographs of them; in one Sara is holding the baby and they are two small things. I realize that her baby has her ears pierced and that she also has a scar across one of

her eyelids. A sadness that is at once striking and lingering emanates from Sara's eyes, but her baby looks at peace, eyes closed, sleeping and smiling. Some children can forget the pain with which they are afflicted. While others break, they bend like we cannot imagine.

Cutters are not only relegated to institutions, though within institutions (mental, correctional) this form of body modification is one that is unmatched. Morbidity can live within the walls of a family home, of a village or within a prison. The question of whether cutting leads to more severe forms of mutilation is one with an answer that is multifaceted. Considering my informants, the presence of these kinds of embodiment troubles (cutting, scarification) do not necessarily lead to more severe desires for modifications, but do frequently evolve into other acts of more radical self-harm. For Adam, cutting was an introduction to the multitudes of modifications he would come to engage in, including the cutting off of body parts. For Tobias, who strongly desires the removal of his leg, he never cut or otherwise self-harmed because he recognized that it would not bring him the result he desires. There is not a necessary trajectory from cutting to more severe modification among the BIID group, but amongst the body modification subculture and amongst institutionalized populations of those who self harm there seems to be a strong link.

## **Embodiment Troubles in Institutions:**

I am lighted as to how significantly institutional the manifestation of this particular form of embodiment trouble (cutting) is through my conversation with Jeff Earl, the coordinator of psychology at a correctional institution who has worked in the field for 25 years. I begin my conversation with Jeff by discussing the debate over naming the embodiment trouble I am predominantly researching- BIID (aka, transabled, apotemnophilia, wannabe) and ask, from his clinical perspective, how important coming to a consensus on the name of a particular disorder is:

*"I tend to look at it from more of a behavioral perspective... labeling the behaviors isn't overly helpful. Looking at what maintains the behavior is much more important. Is it being done for attention, because there are body distortion problems, or a variety of different things- so what we usually try to do, is try and understand what things are supporting the behavior and putting interventions into place to reduce the behavior or stop it."*

This is a very practical approach suited to the prison environment where the threshold for treatment before a condition worsens is expedited, and I recognize that the question I pose is quite philosophical. The power given by a name though, is one that maintains even in the chaotic confines of a prison. There are a variety of reasons that the naming or diagnosis is of particular importance within a prison:

*"One of the problems is that there are a lot of the guys we have in here who are having mental health problems, but they do not have Axis 1 disorders that would be treated in a mental health facility and in the community, so they really fall through the cracks in terms of society and mental health strategies. They have to end up in prisons".*

The inmates Jeff speaks of have not been formally diagnosed with a mental illness. When an inmate is diagnosed s/he is eligible for better treatment than someone who remains under the radar, still diagnoses may be problematic for different reasons; non-necessity, inaccuracy, or as ammunition for an inmate to make particular demands and access particular medications that they may sell or abuse.

Accessibility to information is a problem faced by staff in corrections services and this limits the amount of care being offered to inmates, whose numbers already strain the insufficient mental health resources available:

*“Basically when people come in, in some cases we have a lot of information, and in others we have little. A lot of times people will go to their family doctor and they may have a diagnosis like bi-polar disorder and be on anti-depressants, or attention deficit disorder... In some cases the diagnosis is fairly questionable, and in other cases people have gone through an in-patient placement and had a pretty thorough examination...The other difficulty is that we need the offenders consent to get medically confidential information. So, we go through a lot of efforts to try and get information about mental status, but it is very difficult to get...”*

At the prison where Jeff is employed there are 450 inmates, but because it is the regional reception centre there is large and constant turnover and they receive over 500 new inmates each year. Of these offenders, Jeff estimates that 25% are on some sort of psychotropic medication, and even more are having “some sort of mental health difficulties”. This high ratio of medicated inmates does not come as a surprise: our culture in general is at a high point with respect to the use of psychotropic and enhancement medicines and institutional usage

reflects the situation of the wider culture. Inasmuch as prisons work as microcosms for society as a whole, problems such as cutting or slashing are present on a level that does not correlate, and there are a variety of reasons why prisons are a hot bed for such types of behavior. Within a prison emotions may be heightened to extremes (or numb beyond belief). Cutters or slashers of all varieties find that sometimes if they can focus on physical pain, it takes away from their emotional pain. Self-injury results from someone's inability to manage their emotions. Some may be overwhelmed by situational factors: put in segregation and utterly depressed and angry, denied a parole, their partner breaks up with them... they are upset and angry at themselves, so they slash. Some people will use self harm as a tool for manipulation, something prison employees are very much aware of: "*There are power and control issues...you have to be careful because sometimes there is a pay off and you have to be aware. Someone may be trying to get put in (mental health care facility, rehabilitation area) because they have drug debts, for example*". There are others who are completely delusional: "*We had one gentleman who thought that he was in a reality TV show and slashed because he thought the show would have to stop the program*".

While I imagine most mental illnesses have symptoms which are aggravated in a prison setting, Dr. Armando Favazza discusses two which are particularly related to imprisonment; antisocial personality disorder, characterized by compulsive, aggressive, hostile behavior, which is made worse "*when placed in a restrictive prison setting*" (Favazza, 111), and borderline

personality disorder as *"the only mental illness in which, according to the official psychiatric nomenclature, the occurrence of physically self-damaging acts is a major diagnostic criterion"*(Favazza, 110). Jeff finds that there are *"more and more people with emotional deregulation and impulse control problems, people who have borderline personality disorder traits"*. This serves as a valid explanation for the number of patients who chronically self harm. For these people, dialectical behavior therapy-an approach to help people take their mind off negative thoughts and balance extreme emotions- seems to have a lot of promise, according to Jeff's experience: Borderline patients are a *"very resistant, very difficult treatment group"* and a *"significant percentage end up killing themselves eventually"*.

The frequency and type of self-harm going on in institutions varies. Favazza has written about more extreme forms of self-harm in prisons including castration and amputation. In the following passage Jeff tells of the various forms of mutilation he has encountered in his career:

*"Cutting is most common, we have certainly have seen other people who have burned...one man use to wrap his arms in bags and light them on fire... inserting objects in eyelids- things like staples. We have had people in Atlantic institution that have cut off toes and fingers...never here though...We certainly had people who would self-mutilate with behaviors that could very well cause death. We had one gentleman that would repeatedly injure his genitals and his lower body, his intestines and stomach, he would basically jab things in there and even when he was restrained all the time. At one point he used a stand from his IV to basically poke in there (stomach) and damage his internal organs."*

The frequency with which such behavior arises varies, as Jeff most aptly describes, *"It is a continuum with different topologies within that continuum"*.

Minor cutting is entirely common and likely occurs on a daily basis, while the other more extreme and difficult to perform behaviors are more rare. Jeff's team sends around three inmates to the *treatment centre*, a mental health facility (under law), per month, "*usually because of concerns about suicide*".

Dr. Armando Favazza's writing on self-mutilation and body modification comes from three decades of extensive clinical experience as a cultural psychiatrist. He indicates that, as with other mutilations, the desire to lose one's limb may be a reflection of castration anxiety and other libidinal confusions, as a borderline or schizoid impulse, or as a specific non-psychotic assertion influenced by the transference of a traumatic experience otherwise unrelated (1986). In reading through some of Favazza's case studies I was struck with the possibility that the first sight awakening (the point of reference for their desire is often an early childhood experience with a disabled person) often relayed by those desiring disability may directly correspond to a traumatic developmental experience, occurring at approximately the same time. The transference of this experience into the perceived foreignness or loathing of the body part(s) in question may be forgotten by the individual suffering the embodiment trouble, and come to be understood only as a profound and integral part of their identity. If their psycho-trauma is so centered on their embodiment, their newly achieved sense of wholeness and satisfaction upon the realization of the disability (for those few who acquire their desire) may speak to a greater peace of mind found through abolishing the *symbol* of their trauma and disorder. The complex sexual metaphors found through looking at clinical cases of self-mutilation as told by

Favazza and Jeff share common points with the ordeals of other people discussed in this project who desire to physically harm themselves towards whatever conclusion.

### **Self-Injury in BIID Respondents:**

This section deals in particular with self-injury as it relates to the BIID informant, specifically as an attempt to inflict some degree of the disabled condition they desire. In the media there have been articulations by amputees who have solicited necessary removal of their limb by a surgeon through either purposefully inducing gangrene via the application of dry ice, through shooting the leg, cutting it with a chainsaw (Gilbert, 2003), and even from sitting beside railroad irons. As Claire describes, it is not enough for most people with BIID to pretend, they "*need to need*" the chair, the crutches, the braces. She describes this as more than a psychological need or longing, but an actual physical need. It is evident that the body does not require the change in form to survive, in fact, the change in form is a difficult and compromising shock to the body. It is the psychological drives and desires that so poignantly create the need which makes acts of self-injury desirable. Even when the BIID sufferer has talked themselves out of self-injury they still hold belief in the possibility of someday acquiring their desired form. Tobias is an example of someone who has worked through a low point and talked himself out of taking such action:

*"I was really close to doing something -shoving the leg under a bus- about twelve years or so ago but a really bad nightmare the day before I had decided to "do the deed" prevented me. I considered trying to get rid of a toe or two as that would be so much easier and with less risk involved but*



*as I felt that would really do nothing to solve my problem with the leg I decided against it."*

Of all my interview subjects, the one who seems to be the most at risk for severe self injury or suicide is Sean. Sean has been living in utter desperation for a very long time. He has undergone several traumatic experiences related to his BIID in the past, including being raped by his therapist as a teenager while living in Montreal. He also seems to be the most obsessive about his condition. Sean is the webmaster of a daily up-dated blog forum for people with BIID. He often posts reactions to other peoples frequently cruel blog posts about BIID. His utterly compelling obsession leads him to search out this damaging content, setting himself up for a lot of abuse, thus, the sadistic nature of BIID. Sean has hinted several times that he will likely seek out the "*only other solution*" (suicide) to his BIID. While he reaches staggering lows and often contemplates suicide he has physically self-injured only once in the past:

*"I did attempt self injury once. Tied a 2"x4" to my back and "fell" backwards from a ladder. I bruised my back, gave myself nerve pains in the right leg that lasted a couple months, and that was it. I vowed at the time never to try self-injury again, but now, I'm not so sure. I'm desperate enough to try again, if I found a way that I could rely on."*

According to Dr. First, BIID is a typically male disorder (Gilbert, 2003) and a very aggressive disorder. Claire's experience is unique for this reason, and also reflects conventional gender stereotypes. Her experience with self-injury reflects feminine gender performativity, both in method (more passive) and in that she describes it as not so much stemming from the BIID, but from the guilt of not

really needing her chair- for “lying”. Claire has a guilty ego. Throughout the hours we spend together she frequently comments on feeling guilty about one thing or another. Guilt is another reason Claire feels so impassioned to believe that BIID is a neurological disorder. Of the interview participants, she is mostly firmly rooted to this belief and she expresses it often. She believes wholly in the validity of the McGeoch and Ramachandran research and carries a note from them explaining that they believe BIID to be a neurological condition, in case she may need it again in an emergency situation to explain her case, as with her instance of self-injury:

*“...At first I said that I had back trouble, which was true so I wasn’t really lying to people...and using a wheel chair for that is quite an exaggeration...its really something very common –at first that was explained and as I started to use the chair more frequently-I was kind of searching for a long time, really feeling like I couldn’t lie anymore, researching different disabilities and conditions- how do I say this- how do I explain to people without lying but without telling the whole truth more than I was comfortable revealing. I lighted upon \_\_\_\_ (condition), and now that is what I say. I started saying that and almost the exact same time, when I started saying that, I said that I had gone to see a doctor in \_\_\_\_ and I came home and said, ‘Well, I went to see a doctor, and at home they were not able to diagnose me properly, and that I went to see a neurologist in the States and they said that I had \_\_\_\_ (condition)’. And around the same time I started saying I had \_\_\_\_ I saw how I could cause a genuine case of \_\_\_\_ . Online. I was really, really desperate to achieve-I knew there was no way I could make myself a paraplegic – that it is too, too dangerous and It was also really drastic as far as I couldn’t take care of my family like that, and I couldn’t do that. So I was really desperate to attain a disability that would give me some relief from the BIID and allow me to more legitimately use the chair and without lying to people. I got the supplies from the internet and pharmacy ...and I was really scared and it was really hard. At first I had the needles for a few months and...I kind of scared myself and I put them away for a long time and then I got them out again and I really needed to cause this disability. So it was kind of hit or miss, because you’ve got the needle and this expanse of skin and you’ve got to find the nerve so you have to identify the nerve by pain. And it’s really, really excruciating pain, and it’s really hard. At first I didn’t even think I’d be able to insert the needle into the skin and I practiced and got*

*really good at that. ..My plan actually was to do a lot more than I did, I was going to do one nerve and one on the other side and move further up. I was really going to make it so I needed my chair for most situations. For some reason needing the chair more than just psychologically seems to be a big part of it for a lot of people. I don't know why that is. It's more than just pretending, it's needing the chair- another thing all together. More than psychologically, needing to physically need the chair. Physically. Like, to not be able to get by without it. That's not what happened though. Because, I did this leg, this lower leg, and it just absolutely hurt really bad when I injected it, and after I injected it and it just really got numb. A week and a half paralyzed and it just felt so good. So I had these (leg braces) and it made it so I could not flex my foot, my foot was just floppy for more like 3 weeks, but since I was already wearing these braces, and if I had the brace on it made absolutely no difference how I walked and I was thrilled at the weakness, at the lack of sensation, of feeling like my foot was half paralyzed- and it was great. It was like it felt like that was how it was meant to be, for some reason, a relief, And it wasn't like sexual relief, like I got a charge out of it- it just felt right. It felt normal. But the problem was I started getting nerve pain after that...shooting pain and weird sensations, really painful. I got to the point where I couldn't sleep at night because I never knew pain like that existed...it was worse than natural child birth, and I've had 2...I had to go to the emergency room and because they could see the injection marks on my leg I had to tell them..."*

Claire describes this experience as "a new low point in my entire life." Her marriage began to increasingly unravel, and she does not trust that it will sustain. She is still dealing with nerve pain, but is now on a medication that helps to control it. However, she claims that:

*"Now that it is done and behind me, I do not regret it. One of the major things for me was coming up for a reason why I was in my chair. I LOVE to be in my chair, it is so much a part of me and all this stress about pretending and all that never happens to me when I am in my chair. It is a safe place and basically its relief from the obsession of BIID, I am living my life like I always thought I was meant to be living it."*

Sometimes the injury is inflicted gradually over time, whether loosing muscle capacity by sitting in a wheel chair too frequently, or in the case of Martin

where the result of the injury is considered not only a correction-but *the*  
correction:

*"I always had the feeling my knee is there and I have always been very aware of my leg and my knee. To a certain degree I would agree that now my knee "disappears" a little but... not totally... but a bit. And this is actually happening when a knee joint is fused, the joint is gone. And when you could see my legs, you would see the shape of my right knee has changed, the contour is still visible clearly, but it looks different from the left knee. The left knee looks much stronger and has a "normal", strong contour. In a certain way you can say that fusing my knee is a bit like losing it, it will be gone and is not there, its function is gone, the contour looks different. But, I still have a high awareness of my leg as a whole and it has always been my leg as a whole that is somehow special to me. So you could say, technically it is a knee fusion that I wanted and the resulting straight and stiff leg is the outcome it creates. And that is the true image I have about myself."*

All modifying informants consider physical debilitation and self-injury to be an empowering 'body correction' to some extent. This demonstrates just how non-normative their perception of embodiment is: to 'correct' the body through drastically reducing its functioning. It may seem absurd, but the common experience of the *transabled* is that there is no mental correction available to them. Self-injury to this extent is a phenomena that angers many, and because of this I often find myself defending my informants and the populations they represent. One claim amongst others (e.g. attention seeking / perverted) that is often laid against them is that they are lazy. I feel that this one in particular is a weak, but interesting claim. Lazy people can find ways not to work or even walk, but if you have witnessed an amputee or paraplegic in action you see how straining basic daily rituals can become.

Automutilation is what we call it when animals self-mutilate. We call it this because we are weary about whether animals possess a sense of self (Favazza, 68). I am moved to wonder whether 'otherwise normal' humans are not sometimes just as unconscious; if one's sense of self is of someone far from whom one is, what is a sense of self? Are automatons always submissive to the social order, or has the social order spawned a new sort, those who know their true selves to be something different from what they are, and will undergo drastic means to finally become who they felt they always *really were*. There is something haunting and common amongst all of these forms of, or forms of desire for, self-injury, and self injury is a part of any moniker I have put to use in this thesis (BIID, apotemnophilia, transability...).

## IV

### **Embodiment Troubles, Pretending:**

Pretending in the context of BIID is when physically able people pretend to be physically disabled. This may take various forms; a person desiring to be an amputee may bind up an arm or a leg and wear loose fitting clothes to camouflage it. A person desiring paralysis of the legs may spend much of their public (and private) time in a wheelchair. Pretending is a theme which arose frequently in my discussions with informants- all of my BIID participants have pretended at one time or another, usually in secret as youth and still secretly, but in public as well as private locations, as adults. Sean offers us what is likely one of the most intense cases of pretending ever: he has been living his public life as a paraplegic for the past 12 years. There is often a stark contrast of pleasure and discomfort when pretending. While informants purport to feeling most comfortable when they are in their chair, there is also that "uneasy sense of standing under a sign to which one does and does not belong" (Butler 219 *BTM*).

I walk across the Tim Horton's parking lot to meet a woman who is sitting outside in a wheelchair, waving enthusiastically at me. As I get closer I see an excited grin spread across her face. She has told me she will be middle aged and overweight, but she is only slightly top heavy, the remnants of three young children, and she does not look much more than my 25 years. She appears neat and tidy, is dressed stylishly and is wheeling a slight, titanium chair that cost her

\$3,500 out of pocket: state-of-the-art, purchased online. She giggles and introduces herself, *"Have you figured out where I'm from yet, I've given you enough hints?"* I haven't and we laugh at this, but it is not awkward and there is no tension although I have been nervous about participating in this game of pretending and am about to get a taste of it first-hand.

I have been e-mailing back and forth with Claire for months and though I surely have enough material to go on, the opportunity to spend some time with her in person in her chair is too tempting to miss. We decide to go someplace more private to chat, the condominium style hotel where she is staying. She is seriously uncomfortable with the possibility of anyone knowing she is pretending, but is even more troubled by the guilt that accompanies lying, even to perfect strangers. This has created a strange dichotomy for her to the point where she went as far as to self-inflict an "actual" disability which no longer offers her pleasure or much relief, except from the burden of completely lying. For today, she is faced with a smaller, still difficult predicament of negotiating the two-fold guilt of pretending: On one hand, Claire feels badly for pretending because she does not legitimately require a wheelchair and there are people who do and she knows that they are, for the most part, disgusted with and upset by people like her. On the other hand, she feels badly for pretending because of the demands she must make on other non-disabled people and because of the trickery involved. Claire tells me of a current predicament that illustrates this conundrum:

*"There was a problem checking into my hotel. I requested an accessible room and when I got here I saw that it was not accessible at all. There*

*was a step to get into the main part. That is always really hard. I had to make the decision, well, it doesn't really matter to me whether it is accessible or not, I could get out of my chair and walk in, well, you see, it pisses me off, because they said the room was accessible and it's not. So, for a really disabled person it would be impossible to use that room. So I had to decide-Do I say anything? Do I strand up in this case, for disabled people, or do I shut up because I feel bad about them going to all this bother for me? I called them and they came down, and immediately came down and built a little ramp. Now there is no way I cannot use my chair here, you see; if they saw me walking!"*

Claire expertly wheels herself across the busy street into the hotel parking lot and over the ramp to her ground floor room and is faced with another concern that would be a genuine problem for someone with compromised mobility; her room keys won't work. Suddenly she springs into action to get into her vehicle, the whole routine takes less than a minute: Claire hops from her chair into the driver seat, pushes back the passenger seat, pops the wheels off the chair and tosses them behind her head into the back of the van. Then she grabs the chair and, holding onto it with both arms, leans backwards placing it behind her, she readjusts the seats and is off. It looks exhausting to me and there is still the dismount to consider, but she seems to enjoy the whole process, a wide grin firmly planted on her face. We drive off to the main building to retrieve new keys. I am hyper aware of people's reactions to us as we enter the lobby; they watch Claire with restrained curiosity as she busily maneuvers her chair. They seem slightly horrified as they listen to her predicament and return her a new set of keys. Again she is popping the wheels off her chair and tossing the whole bit into the back of her van. We arrive back at her room in a few minutes and there is a problem with the new key cards, they don't work either. This time Claire calls the



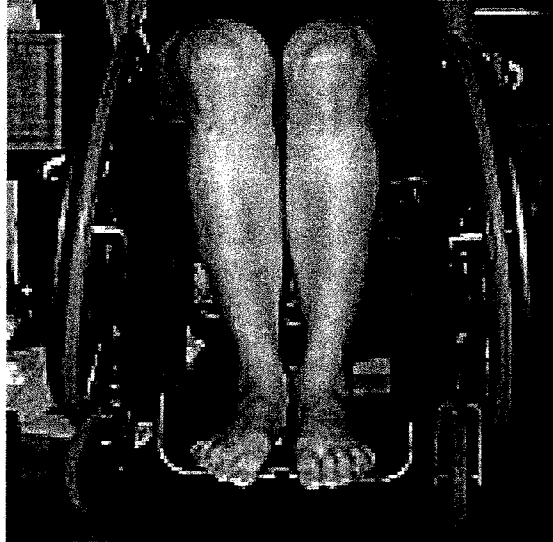
administration and in a few quick moments the proprietor is there, flustered and apologetic. I find myself looking at him disapprovingly and suddenly feel like a pawn in the game, a bit of the guilt Claire speaks of creeps in and I smile at him and shrug my shoulders as he rushes off to fetch yet another set of keys.

*"I don't know why they said they had a room that was accessible, it is still not really accessible"*, Claire tells me as we settle into the kitchenette to begin our main discussion, *"the bathroom is totally inaccessible and if I was really disabled I would never be able to turn the air conditioning on."* She demonstrates by hopping up from her chair and turning on the air. Seeing her walk across the room produces the first flash of anxiety I have experienced since meeting Claire; it is almost as though I came to expect her to be *really* disabled. Suddenly I am seeing in front of my very eyes the schizophrenic reality of the problem. I notice that the bed is also quite high and that a truly physically disabled person of Claire's stature would likely have some difficulty getting to bed tonight.

Claire is not yet using her chair full-time and has only been using it for 2 years. She takes every opportunity she is away from home to wheel and has several excuses to feed skeptics and those who know her who question why she owns a chair and why she sometimes uses it. For Sean, who now lives "full time" in a wheelchair, wheeling was a much earlier part of his experience with BIID:

*"In my mid teens, I rented my first wheelchair. An old clunker, which at the time was pretty much the only thing available. I remember having trouble finding money to pay the deposit, but somehow I managed. I also hid that in the basement of our apartment, and escaped every time I could to use it. It wasn't difficult, my mother worked evenings a lot. I don't recall very*

*well what I felt when I first sat in that wheelchair...I do remember a lot of anxiety and fear of being discovered. I had to hide in the basement, I didn't have much space to move about, I didn't really have anything to do. Yet, it was an important part of my growing up with BIID."*



A photograph of Claire in her wheelchair

Claire has found the cliché of delayed gratification to be realized. This excerpt is comprised of sections from her blog dated November 10, 2006. In it, she presents in vivid details her account of the first time she purchased and used a wheelchair of her own:

*"I was afraid, unsure...Because if I didn't have BIID, then this was pointless, and whatever was wrong with me, the chair wasn't going to help, and I had gone through a lot of anguish and expense over it for nothing. And if I did have BIID, then this was like saying "I do" and till death to us part, I'd never be free of it...I stared at the chair...I took a deep breath. Stood up. Pushed my office chair out of the way. Rolled my wheelchair over to me, positioned it in front of the computer. Took another deep breath. And sat down...my universe had indeed shifted. It was off by a few degrees and it made a slight shift and suddenly it was right. I was filled with this unbelievable joy. A feeling of completeness, of rightness, of relief. I felt, rather than heard, a door slamming behind me, the lock turning, no going back now".*

Claire's new-found comfort via her wheel chair echoes the assertion of a wholeness or completion (in terms of identity) that so many BIID sufferers express when they realize their imagined embodied form. As Martin told me, "*I am now living my dream*".

A sensitive issue in all of this which Claire has alluded to and which cannot be ignored is the act of pretending in contrast to the reality of disability. The act of pretending seems utterly bizarre, if not offensive, particularly to someone whose limbs are subject to accidental or necessary amputation or paralysis. As one would suspect, it is difficult for those who live through the burden of real physical disability to empathize with those who suffer an ailment that is so unbelievably odd: those who do not only *not* appreciate their physical well-being but loath it and consider it a disadvantage to their overall well-being. This is a popular topic of discussion amongst the participants on online forums, many whom have spent much time convincing real disabled people of their kin disability (the mental one) that requires that they desire a physical manifestation often resulting in pretending. As Claire reveals, "*Based on my experiences talking to people who have a physical disability about BIID, that whole community is very much against pretenders and devotees and stuff like that*".

There are many transgendered people in disagreement over the proposed similarities between their desire for a gender other than the one they physically represent and BIID persons' desire for a physique that represents their "genuine"

identity. Many disabled people are more than “against” pretenders: they are outright outraged at the prospect of people with BIID merely existing. One of the reasons for this seems to be the apparently perverse nature of pretending, the notion that people do so because they are sexually aroused by it. Another widely shared belief is that people who desire to have sexual relations with disabled people want to dominate them and take advantage of them because they are weak or “crippled”. Clearly, this is not a popular group to draw alliances with.

While I am entirely sympathetic to the arguments put forth by physically disabled people, I am not surprised that after lengthy discussion with pretenders some transform their outrage and disbelief. Sean is one example of someone with BIID who has shared a significant relationship with a physically disabled person who was at first shocked, then came into a sympathetic understanding of his condition. Claire has a friend who is physically impaired and in a wheel chair who is “*fairly open minded*” but who still “*has discussions*” with Claire about this. Their heightened sense of forgiveness is not as unlikely as it may seem. It is not that people who suffer from BIID take for granted their mobility and physical health, but they are far more concerned about the impact not realizing their ideal embodiment has on their overall health and productivity. They consider themselves mentally disabled and incapable of living true, content lives, and do not see the remedy as a cruel catch so much as they consider their lack of treatment options the cruel reality of the situation. This was one of the more surprising realizations I had about people with BIID: I expected quite a lot of disdain for the affliction, yet there was very little self-pity in terms of *Why do I*

*have to have BIID? However, there was quite a bit of frustration expressed in terms of Why can't I get the help I need for my BIID?*

## V

### **Embodiment Troubles, Self:**

#### **Identity vs. Sexuality:**

Questions of selfhood and identity are usually bound to questions of sexuality. The choices we make are not immune to any aspect of our identity, we are our sexuality, though we may not acknowledge this or realize it on a conscious level. The consideration of the sexual nature of BIID (in this sense usually considered apotemnophilia) is one consistently revealed in internet forums, but not one often probed by the interviewers in the literature and media available. When we use the language of identity, selfhood, and desire, we are inevitably speaking of our sexuality; as a part of our real or ideal self, as a driver of our desires. If we do not probe the specificity of this discourse in the further consideration of embodiment troubles we will come no closer to an understanding of the complex and compulsive drive for these radical transformations of physical being. The identities of those with the embodiment troubles discussed here, much like those seeking gender transformations, are often complex and seemingly individual. Just as a transsexual man may identify himself as a woman trapped in a man's body, he may still desire a woman for his sexual partner post-surgery. He may consider himself a lesbian trapped in a man's body, or some other gender identity mash-up. Similarly, distinctions between amputees, wannabes, pretenders and devotees are often unclear and simultaneously very specific.

The quest to belong to a group is to identify with particular meanings through symbolic processes. Normative heterosexuality stands in as the base group to which the majority of embodied subjects purport to belong, through a persistent, unconscious “performing” of the historic socio-political construction of the modern subject. Evidently, within sexuality there is a spectrum of sexualities that seems (with the mind-blowing continuum of pornography available in cyber space) infinite. If identity is contingent on the base difference of sex, does this mean that other differences are born of that essential difference? If so, what are the intricacies of this process of signification: are these created differences caused by the base construction of sex, must they always refer to it, and are they derived from it? (Butler 167 *BTM*).

Differences in embodiment are primers for identity, and through these physical differences we have come to accept a whole economy of differences that are contingent upon various illusive constructs. I do believe that biological differences are important in the simple fact that we are embodied subjects, and our embodiment is an incredibly valid component of our subjectivity, regardless of what constructs we believe our bodies’ aid in prescribing. The insistence that there is an essential difference between problems of identity and problems of sexuality is one that dissolves almost immediately upon closer examination.

In *Bodies That Matter*, Judith Butler discusses sex and identity as a singular construct contingent on the paternal law. She uses Slavoj Žižek’s idea that the (postmodern) “*phantasmatic promise of identity as a rallying point within political discourse as well as the inevitability of disappointment*” (Butler 188

*BTM*), makes identity claims “*impossible*” (Butler *ibid*). Through her discussion of Žižek’s definition of identity a point of interrogation common to my interviews emerges: regret and disappointment are qualitative of the postmodern concept of identity. This is an idea simultaneously shared and refuted by my informants who view their actual embodiment as a severe disappointment and in the same breath are satisfied beyond belief with their transformation of embodiment after they attain their desired form. They refuse the possibility of being disappointed in an identity that they have always maintained as Real, through its constant contestation with reality.

I am certain that there is a sexual element to BIID. It is a problem far more complex than a sexual preference or perversion, still, I do believe that it is quite possible that it is sexual in essence and becomes inflated as it intensifies and morphs into the primary aspect of the identity of the “transabled” person. There is much attention paid to the fact that the sufferer of BIID is otherwise “normal. The fact that informants very strongly consider their identity as primarily that of a BIID sufferer or their body image as primarily that of a disabled person, is highly problematic and it is an assertion or belief that engulfs their whole life. During a conversation with Claire I told her that when I consider identity as it pertains to my embodiment, I primarily conceptualize myself as being a woman- my female body. I ask what her primary conceptualization of her own body is. She answers, “*I would say that its more about being disabled than being female...I never thought about that like that, but that’s what it is.*” Claire who is only very mildly physically disabled (many would not consider her self induced affliction genuinely



debilitating), who has birthed three children, who has lived as a subject in her individual embodiment (give or take some minor modifications) for almost 40 years, is so compelled by the desire to be disabled that it has usurped her body image. This example illustrates how deeply afflicting this problem can be.

I am not surprised when my informants assert that BIID plays no significant part of their sexuality, I have almost come to expect them to. I understand that they perceive particular possibilities as being extinguished if BIID is slotted into a fetish category as opposed to a legitimate and distinct mental illness. What does come as a bit of a surprise is how transparent this assertion seems when engaging in dialogue about their psycho-sexual development and in reading over interview scripts. This is not a problem of intentional manipulation, rather, informants are genuinely confused about the nature of their problem, as is most anyone who closely examines BIID. While many initially present a seeming deeply entrenched idea about why they have BIID (e.g. Claire: neurological problem), conversations reveal the complexity and pervading sexual element to their obsession. The following passage comes from Claire, talking about her course to BIID:

*"I thought it was... I had a special appreciation for people who were disabled and... I never really subjected my desire to be disabled to a whole lot of questioning, I never really understood it but when I was younger it never really tormented me a lot either. It got worse as I got older...didn't ignore it; I just did a lot of fantasizing. I never told anybody...even now it's kind of hard to explain for me. I really don't know why I never told anybody, but I knew it was unusual, and even now after I've done a lot of reflecting and it wasn't until, well, with the advent of the internet I started doing research...I found this chat room for people with disabilities...I was like a regular...that was the first I had ever heard about wannabes or devotees... I didn't even, I always knew I was really attracted*

*to people with disabilities and I had no idea that there was more than one human being on the face of the earth who felt like that, and in this chatroom, like in one breath they told me that it existed and then how creepy and evil and disgusting it was. I repressed that for a long time, and the wannabe thing... I was really ashamed- Oh my god, I didn't realize I was so awful and so disgusting! I felt a lot of shame and I sort of repressed it and I thought, that's not me, I'm just really interested and I really care a lot about those people... I never met anyone, I would have though. There was a guy at school who I was really attracted to who is in a chair but nothing ever happened...but I would have though. I would have had no problem with that."*

Martin also presents a response to my inquiry that is explicit about a separation between sexuality and identity. I found some irony in this when looking at this photograph that Martin sent me of his fused knee. It reminds me of a pin-up type photograph (perhaps it's the bulge or the shoe?) and gives me a sense of the aesthetic of his leg as being one that is sexualized (Granted, this may be my perception and not his intent or underlying desire).

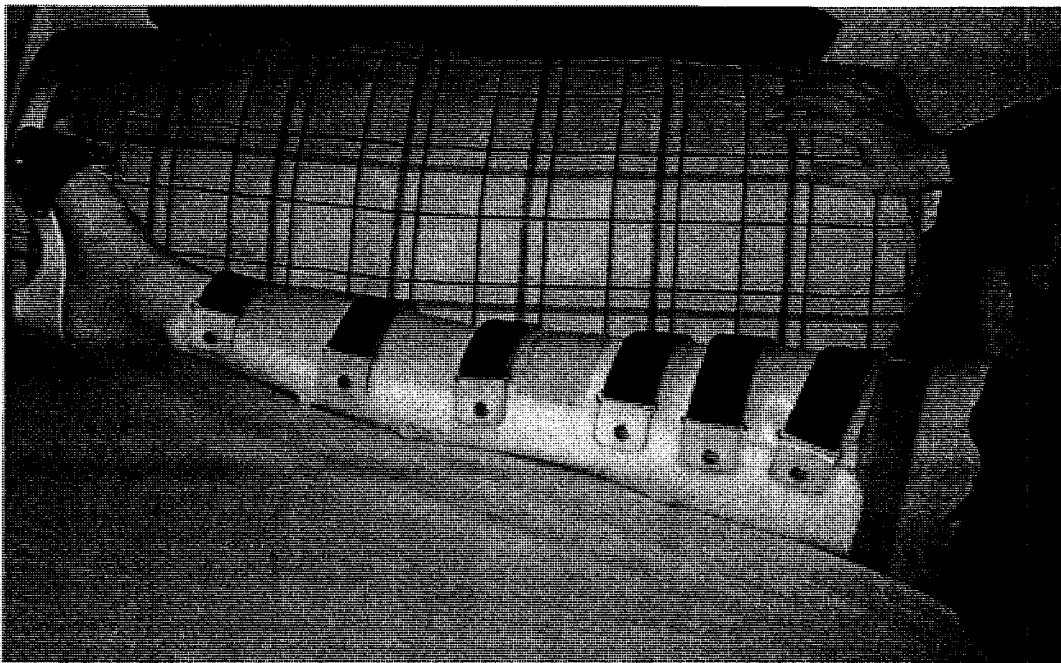


Image of Martin's fused leg (2008)

I ask Martin how his sexuality relates to his knee fusion and whether he is aroused by this or other disabilities. He answers:

*"This question cannot be answered with a simple yes or no. BIID is part of my sexuality. But, my blood pressure between my legs does not go up when I see a disabled person, it is more an emotional arousal rather than sexual. Nevertheless, it is part of my sexuality. I cannot have a sexual relationship without my leg, it is part of it. I firmly believe, real BIID relates to Gender Identity Disorder. Being trapped in the wrong body does not only apply to the gender as in GID, it can also affect limbs and then we talk about BIID, but many underlying things are the same. You may talk to transsexual people and you will suddenly find common things you may have never expected... This why BIID is not a paraphilia, it is much more, it is much more complex as you can see."*

Claire agrees that every person with BIID is not necessarily a devotee or vice versa, she abides by a BIID spectrum, much akin to the gender spectrum I mentioned, whereby there is room for a plethora of transecting identities. She does not believe, however, that people have much control over where they fall on the spectrum. I agree that this may become the situation as an unfulfilled desire can grow to inflated proportions and become a compulsive obsession. Informants do not accept this trajectory as the reason BIID feels like an identity problem that is much more significant than a sexual problem, but within every interview there was a clear link between the desire for disability and a sexual attraction to disability. This relationship was almost always initially obscured by the informant. Again, I posit that this is reflective of the information informants have accessed, the language they have learned to use to describe their desire, so that it may gain validity by sounding as real as it feels to them. Tobias provided me with a

standard example of this strategy: *"What I want, need, is my left leg off above the knee. I know more or less exactly where on the thigh it should end. That desire in itself I don't feel is sexually motivated"*. When I asked Tobias some questions about his sexual development he said that he began masturbating at the same time as most boys do, *"in combination with pretending"*.

We are sexual people in one way or another. We may assert the power of other devices over our libidinal drives, but they will always be revealed in some capacity. I could debate an eternity over the differentiation between sex and identity, and the following passage serves well to illustrate the probable tautology of that debate. Claire expresses a sexual attraction to disabled people and simultaneously asserts that her interest is fundamentally not sexual. Over time, the questions ware into more confident confessions and she becomes candid about the sexual aspect of her desire:

*"...I am on a forum for female devotes...I actually think it's a paraphilia-being a devotee. Earlier we had talked about- does it have to be a paraphilia to be attracted to someone with a disability-and I think it's a paraphilia because you can't control it. You see someone in a wheelchair like a parapelegic, like a hot Paralympic type guy and you're heart starts beating and you're like (panting)...I think it's connected because there are so many people with BIID who are devotees."*

*"...A sexual element (lowers her voice to a whisper) after I had started using my chair for a while and I started going to school regularly, like twice a week -I started to get sexually aroused as I was on my way, driving... almost an anticipation of being in my chair. And once I was in my chair it went away. And it didn't happen until I had had my chair for a long time. It wasn't my reason for starting wheeling....I didn't want it this way, I always said that it's not sexual and I certainly didn't want it that way...I'd get to school and have to get out my chair and get to class and I just wouldn't think about it, it would leave my mind."*

Claire's articulation brims with sexual excitement related to being disabled *and* to other's disability. She envisions her immobility from the waist down: legs, not including genitals. If this example seems extreme, it serves as a considerably more severe embodiment of psychological trouble when a fundamentally sexual desire can manifest in the proclaimed *need* for a form of such intense libidinal regression as the desire for paraplegia: wanting to surrender sexuality, or to be sexual in a permanently submissive manner, lifeless from the waist down, as with Sean. This may be the result of an utter disruption of psycho-sexual development resulting in obsessive and destructive embodiment anxieties so fundamentally entrenched in the being that he will become an obsolete body to achieve this most tragic notion of comfort. He will voluntarily become incontinent and impotent under the premise that he has no other choice but death.

I question an anonymous informant, who performs castration (among many other) procedures on body modification clients: *Who desires to make their sexuality obsolete, and how are you able to perform these life-turning procedures that null and void their genital libido?*

*"Most of the time its people who take part in heavy bdsm (bondage, domination, submission, sadism, masochism), most of them are submissives and most of the time it is because they do not want to derive pleasure sexually...Well, it's because the-, people who are into heavy bondage play and whatnot- they derive their sexual pleasure differently; they do not derive it directly from their genitals. And for a lot of them chastity and forced chastity are also a big part of the fetish. So, to heighten yourself sexually- it sounds weird- but you have to nullify your libido in that way so you can get off in different ways...For some people different parts of their bodies are really where they get their sexual pleasure and sexual stimulation, it's not from their genitals,-they find their genitals distract from that pleasure."*

If there is a larger social peril at work here it may be that we have long ago reached Barthes's conclusion that sex is "everywhere except in sexuality" (1983), and come to, as Baudrillard acknowledged, a period in which there is no longer sexual liberation- where desires are transferred onto objects and these objects become the site and actor of desire. The objects in question may be the objectified limb set to rid (in the case of Tobias) or in the disabled embodiment one longs for (Claire). These interpretations of object demonstrate the possibility for their being grounded in selfhood-as sites of subjectivity, a possibility that may inevitably leave us all abject. If we transfer our desires onto objects or completely objectify our relations of desire we may find that we are no longer involved in reciprocal sexual relations, but in purely phantasmagorical inflations of forbidden desires. These desires mutate our relational capacities and usurp our control, becoming fetishes or other problematic sexual desires. For example, the wide spread use of Real Dolls™ (life-size, anatomically correct, silicon "love dolls") for sex demonstrate the power of pure objects to seduce the apparent subject (Ashton, 2007).

The apparent *reality effect* (the omnipotence of hyperreality, which allows simulation to appear more real than real, confusing what is real to the point where it is now impossible to discern) that empowers these objects to usurp the sexuality of their embodied subjects represents a fading of sex's reality effect. I am reminded of Baudrillard's rhetorical conversation in *Forget Foucault* on sex and pornography in which he writes, "*Sex itself becomes involuted and disappears as a strong referent in the hyperreality of "liberated" sexuality*" (*ibid*,

14). With the reciprocal, biological relation removed from sex, the chosen paraplegic (dis)embodiment represents liberation (as with prophylaxis in sex) of that supreme sort of safety reality (no biological risks in sex) that can only be described as an illusion, one that will likely not dissipate the libidinal regression.

### **Speaking the Embodiment Divide:**

The health of our population is subject to the disturbing collaboration between pharmaceutical and insurance companies, governments, researchers, physicians, and consumers. This system incorporates diagnostic categorization criteria- part of a medical language accessible through communication with clinicians and the internet, and reimbursement agendas- into its discourse.

Theodore Dalrymple, a writer, psychiatrist and former prison and inner city physician discusses the “proletariatization of doctors” (2007) at the hands of the government. The effects of this phenomenon result in doctors experiencing a great loss of autonomy in recent years and this has resulted in a loss of control over protocol, questioning of patients, time management and the selection of new doctors. This turns physicians into “clock watchers” who treat patients like “parcels on an assembly line”. The change in profession combined with the promotion of easily accessible consumption of anything and everything qualitative of a neoliberal agenda paired with the constant human drive towards perfection allows us to access medication at an unprecedented level. This may seem to contrast the self-reflective nature of the language of selfhood, a point recognized by Dalrymple (2006): *“It is curious how an age of public self-*

*revelation, and of the use of psychological jargon, should also be an age when self-examination is rarely practiced".*

The effects of the conglomeration of these systems are all around us. I first became aware of the effects of this on a corporate level while work for a high end catering company. A large portion of our business was putting on elaborate dinners for groups of doctors from different practices who would hold the dinners in their homes, co-hosted by various energetic, handsome, well-dressed and charming pharmaceutical representatives. They would dine on lobster, steak, fine cheeses and wines, prepared by a set of chefs in their whites, and served by myself and other immaculately mannered servers. Somewhere between the hor d'oeuvres and appetizers there would be a fairly short presentation followed by a brief question period. Before I discovered the purpose of such dinner parties I went about my business helping in the kitchen, filling wine glasses, tossing shrimp tails. Once I realized who was footing the bill on these evenings, I opened my ears and quietly listened. I knew something was being sold, but I was naïve about the flair with which drug companies pimp their wares to prescription pad carriers. The presentations were laced with triumphant testimonials and trial success stories. Samples were distributed, more glasses were emptied, and all in all this portion of the evening was kept brief. Of the drugs I took note of; there was an asthma puffer, an acute back pain killer, and a couple of psychopharmaceuticals. The bills for these evenings were of the intimate wedding variety. Corporations make big money- these dinners had to be paying for themselves and more. This was the first time I realized the extent of the



lucrative relationship between physicians and pharmaceutical companies, and became interested in our own keen collaboration with our physicians to access the treatments we desire. As Claire expressed, *"We want treatment, we want it to have a name, we want it to be studied. I want it to be in the DSM."*

The desire for the symbol of legitimacy that participants recognize as BIIDs inclusion in the DSM, also stems from the human desire to name as an identity-affirming act. Judith Butler discusses the role of naming on our identity constructs:

*As a consequence, the name mobilizes an identity at the same time that it confirms its fundamental alterability. The name orders and institutes a variety of free-floating signifiers into an "identity"; the name effectively "sutures" the object. (208 BTM)*

This *"suturing"* of the disabled identity is the aim for my informants. They very much want to be contained by that identity label, its radical otherness and all the effects it endures.

In his inventory of our preoccupation and gluttonous consumption of enhancement technologies in *Better Than Well, American Medicine Meets the American Dream*, Carl Elliott explores specific cultural conditions which may be responsible for producing certain medical conditions. Elliott considers the language we use in speaking our identities, such as naming, key to coming to an understanding of why we so hungrily consume psycho pharmaceuticals, cosmetic surgeries and intense physical regiments. What is most interesting about the way we describe our modifications is the linguistic reflecting the

psychological division of ourselves into a sort of 'before' and 'after' persona in which the latter, the one enhanced artificially, is the more true self. Elliott reveals of his interviews with enhancers (body builder, Prozac user, self-amputee), "*In each case the true self was the one produced by medical science*" (211).

When we speak about our desires, we are speaking about something that comes before language. After entering linguistic communication we are always bound to the expression of these desires and when those which we attempt to express are unspeakable, the use of metaphor is a necessity of language. This pertains to the Cartesian divide remaining so strong semantically. In the following passage Martin explains his youth hood involvement in physical activity as a metaphor for his crisis of embodiment. While metaphor may be the only way in which we might begin to express our subjective realities, an understanding of metaphor as a tool is often forsaken. It seems that the usefulness of metaphor provides fodder for the presentation of a highly disconnected thinking/being, the embodied subject who sounds disembodied.

*"I did not belong to any special group... Actually I did a lot of sports when I was young. Especially the time when I was 14 and 15. Back then I was doing so much sports. Today it is my opinion that at that time I was literally running away from my true self. I was running a lot when I was 14, but one day I stopped doing sports from one second to the other. I could not get rid of the real image I had about myself. I could no longer run away from myself. But, of course at that age I had no clue how I could ever struggle to get what I need so much, I just knew I cannot run away from it and finally stopped to run away. So, doing a lot of sports was not only fun, I think it really was a metaphor".*

As I have stressed, the usefulness of the distinction between BIID as a sexual problem or an identity problem and the viability of this distinction is, in a

way, the plight of this issue. I believe this is why the language of selfhood is so ingrained in metaphor when describing embodiment troubles. The language of selfhood articulates the mind and body as two distinctly separate entities capable of abiding by entirely different schemas (e.g. *I just don't feel like myself, Even though I am overweight I have always been a thin person inside*). This metaphorical consideration maybe one that is not only deeply entrenched in our language, but one that has the propensity to work somatically, as the possibility for the mind and body to work in opposition schematically. This possibility finds a compelling case in the incident of phantom pains.

When researchers began to explore the phenomena of body image, they looked to phantom pains as a particular instance in which the body image (the part of the brain they determined is responsible for the way we see, or conceptualize our bodies), and corporeality are incongruent (Ramachandran, 1998). In the BBC documentary "Brain Story" (2000) we are introduced to patients experiencing phantom limbs long after their medically necessary amputations. The patients may try to stand up from bed after a leg amputation, or scratch with a finger or hand that is no longer there. While scientists are still somewhat baffled by this phenomenon, they can locate the region of the brain responsible for body image (within the right parietal lobe) and observe that it is not necessarily affected even by radical embodiment changes. The amputees once had the limb in question, and their brains have learned its embodiment and are trained to know the intricacies (nerves, muscles...) of the limbs. People who feel that their limb is foreign or incompatible with their body image do not have

the same experience of a sudden wrenching disconnect between the brain's body image and their embodiment in its changed form that those who experience necessary amputation do. The part of the brain responsible for body image in BIID people has always represented the limb in its natural usefulness. While neither (voluntary or necessary amputees) are brain damaged, they both suffer embodiment troubles which are tangible to them alone.

Adam describes the desire to experience a new sensation in the form of a phantom finger as his primary reason (beyond aesthetics) for removing his digit. Claire tells of an occasion on which she asks whether other members of "transabled.org" consider their situation a reversal of phantom pains and she received mostly negative responses. Still, all present a philosophy of like discordance between the mind and body schemas as being a legitimate claim for their "transability". Perhaps they do not interrogate the philosophical argument against their predicament because they are living it.

Access to articulations of experiences such as the subjects of *Brain Story*, on *transabled.org* and others, and the abundance of both diagnostic criteria and the language of self and subjectivity do not mean that embodiment troubles are the direct manifestations of the saturation of digital connectivity and the resulting availability of the language used to diagnose and divide, but that they are at the very least reflective of these communication mechanisms. The internet gives us a template to learn to belong to particular medical groups. Dr. Schwarz offers an example of this when considering the role of the internet on the medicalized

language of patients as their way of speaking relates to the success of their access to surgery: *"It becomes a play with words"*.

## VI

### **Approaching Theory:**

In rethinking the persistent peril in sociology of forgetting the body as a social/biological/environmental entity, this sociology of the body is the sociology of self and subjectivity. I look at these bodies as they are: the subjects' total embodied experience. I also consider the metaphorical ways we speak about our bodies, and consider these experiences as telling of a wider condition in which we now live. The body is a consistently employed metaphor for almost everything, but out of the usefulness of the body as metaphor we seem to have come to forget ourselves as wholly embodied subjects. In our thought and analysis on the sociology of the body we too often perform the Cartesian dissection of mind and body (Ozawa, 2002), which has facilitated this sort of physical embodiment of schizophrenic divides, manifesting in radical negotiations of embodied space, marking contemporary multiplication of the 'grotesque body'- be it through obesity, self-amputation or any other 'obscene' reconfiguration.

There is an abundance of very compelling contemporary theory which does not address these phenomena in particular, but which possesses possibilities for explaining severe embodiment troubles. As my project began with an interest in exploring particular theories through the example of radical modifications of embodiment, I will discuss these main philosophies here.

## Kristeva:

Beginning with the subject/object relation in the work of Julia Kristeva, the subject is devoted to the traditional triad of oedipal confusion as presented through psychoanalysis. Kristeva breaks from Freudian thought in her urgent re-positioning of the m/other through her advancement of feminine consideration into the foreground by emphasizing the role of the m/other. Kristeva finds that it is insufficient to consider the mother the object (of desire), because she is bound intrinsically, and partially (by her biological reproduction, to start), to her role as subject. Specifically pertinent to this analysis is the case of the 'ab-ject' as discussed in *Powers of Horror, an Essay on Abjection* (1982): that not quite subject, not quite object, who has failed at sufficient separation from the m/other and orientation into their independent subjecthood. In order to become an adjusted subject one must come to look upon the mother as the abject, not with disdain or contempt, but as one which we came from and were physically one with, and concurrently separate from and autonomous of. Confusion over this hazy position is the plight of the abject.

Abjection also extends to any life course corporeal tensions: Kristeva employs the example of "dung" as the become-abject which drops from the subject (*ibid*, 3). Likewise, the self-amputee 'drops' that which is neither s/he (as s/he conceives her ideal self) nor apart from he/r: the loathed appendage. The abject becomes such through the incompleteness of this symbolic process (successful subject's division from mother and father) and comes into a profound fascination with a particular horror: in his case, one's own body as a functional

whole. The self-amputee abjects himself, and moreover, *is* the very abject in question: Observe the horror with which we encounter the drastically modified. Whether the embodied subjects remain plagued with neurosis, or become psychotic, lies in confusion of the paternal law in the adoption of a physical transformation representative of an embodiment of the castration anxiety expressed through the castration of the abject appendage which the anxiety has been transferred to, or a full (or almost complete) libidinal regression that calls for the symbolic nullification of any form of genital sexual engagement: a complete liberation of the psycho-sexual repression that plagued whatever problematic stage of the informant's development- their unspoken, reenacted trauma.

The abject plays out a dramatic alteration of embodied borders, emblematic of their confinement to the margins of society, just as Kristeva articulates her own experience of abjection in its most common form of food loathing when she encounters the repulsive "*cigarette paper thin*" skin on a drink of milk, "*my body extricates itself... from that border*" (*ibid*, 2). Newly embodied borders exemplify radical interpretations of the abject as "*something rejected from which one does not part*" (*ibid*, 4), radical in this particular case in that the abject does physically part from its abject limb in the sense of a disembodiment (amputation), while simultaneously remaining the abject par excellence.

When coming from a standpoint partially structured by psychoanalytic theory the researcher approaches interview subjects from the position of analyst. She pretends at speaking, or at least locating, the unspeakable. This is unavoidable, as we do not only read theory once the research is over.



Throughout the research process, to test our theories accordingly, we must create an atmosphere for discussion that entices the participant to delve deeply into their psyche (in this sense when I do interviews I play at being the analyst). As I interpret answers and flow the interview accordingly, I am doing the detective work of the analyst, prompting my subject to search their unconscious for the roots of their desires, to speak their abjection. A gift of psychoanalysis is that the intimate nature of discussions surrounding embodiment allows for patients to reveal their unconscious fears and desires without much prompting. At the beginning of my first interview with Adam, who performs various body-modifications as a profession, is heavily modified himself, and is on the cusp of a (self)digit amputation, I ask him to frame the trajectory of his relationship with body modification, to locate his primary experience. He describes how at eleven he began cutting or piercing himself and keeping a meticulous log of these experiences written behind his bedpost:

*"...Really, it's like, it's weird. I'd have the sensation part in my head where I knew I needed to do something or like pierce something that day or like do a cut on myself. For some reason I would always write it on the wall behind my headboard and years later when I saw it, it was all like, it was the anniversary of my brother's death at that time and the next time was another significant date and I never really consciously thought about it, but I would mark myself on these dates and later on when I was looking at the dates I was like; Oh my god! Oh my god! I never realized it was serious. I never really thought consciously like I want to get a piercing. It just happened when I was young, it was an instinctive thing. It was like 7 or 8 years later when I went to visit my parents and I was like; Oh wow it's still there, and I looked at all those dates and I realized. I think it's instinctive to mark your flesh, and at such a young age too, I never really knew. Now I realize when I feel a sensation I can look at my life and see what's going on and see where the desire stems...when I looked at that wall I realized this is the way I have always been."*

Adam mentions at the beginning of our conversation that he had begun modifying at around 10 years, but did not elaborate until after a revealing couple of hours of conversation in which he spoke candidly and assuredly. At this point I asked him to return in memory to that early transitory period and consider it in relation to his changing (pubescent) body and anything else that might have been affecting him at that time. I was fascinated by his contemplation of the various dates. Adam worked out that he had created a pattern of marking the heaviest experiences in his life on his unconscious, skin, wall, conscious.

While this revelation may not seem a task of *deus ex machina* caliber, as the plight of the abject, he was coming into much more than a symbolic recognition of his embodied legacy. For Adam, the cyclical game of trauma that characterizes abjection emerges in the primal embodied experience of experimenting with abjection (the marking or injuring of his body), and the much later realization of that abjection for what it was, and even still the later acceptance of what he had then realized, allowing for the on-going trauma of interrogating his drive to modify his embodiment. Adam's self-reflection does not extend to the point at which his desire is considered malevolent or disposable, nor is it nullified. Rather, the apprehension concedes the immediacy of the drive to become a point of contemplation. It does not go away, because it never was simply a matter of locating the desire. This is the mistake we make when we consider speaking the unspeakable *the* analytic process. If this is the case we do not bend to see that abjection has morphed from a metaphorical maternal relation and its (dis)embodied correlates into an integrated social of abject bodies

navigating the uncanny terrain of subjective relations, as exemplified by embodiment troubles. This is our contemporary condition. For this particular group (body modifiers), fulfilling desires becomes the means for working through them. Because Adam interprets the drive as both related to his own experiences of abjection and an aware and assertively hedonistic desire for new sensations he problematizes his own analysis.

**Baudrillard:**

In working through the bulk of Baudrillard's writing as a challenge both intellectual and otherwise, I have realized that his work, whether dealing more directly with the political, aesthetic or technological, offers us very compelling interpretations of contemporary bodies. The usefulness of a Baudrillard begins for this project with his writing on the subject/object problem. Analysis of the subject object relationship meets any project in which research is aligned with a consideration of aesthetic properties (in this case, embodiment).

The elective self amputee may be seen as succumbing to the seduction of their self conflated object- the appendage of their obsession. In this sense (through a metaphoric implosion of the body as subject/object/object) the body remains obsolete but can be seen as such in a new way, a way for revenge of the object, whereby the created body has reversed its subject's embodiment. As Tobias simply puts it; *"What I want, need, is my left leg off above the knee. As things are I want to live my life as an amputee with everything it entails."* Tobias's left leg is the object that has usurped his rightful subjectivity as a four limbed

embodied subject, by the seduction of a complete obsession that transfers his fears and anxieties onto his leg. His leg is the symbol for the fears and anxieties that form the specific obsession, and more than a symbol, his leg becomes the obsession worth ridding through the literal act of amputation.

We disembody through a postmodern perversion of material forms, dramatically altering the way we look through plastic surgery and other processes. We are confused by our embodiment and this confusion reflects the tendency to look at our bodies as projects engaged in the near-constant refutation of age, disease, and ugliness, forgetting that our bodies are natural forms subject to constant and essential change. Our confusion comes in part from the hyper abundance of methods through which we can play with our identity and embodiment courtesy of the World Wide Web. The internet is more than a mirror to the social: it is a parallel social world that threatens to absorb our lived embodied experiences, if it has not done so already. Baudrillard explores how our thinking has been crafted to work within such dualities as mind/body, which may only stand for the existence of reversibility (if A may be opposite to B, A may be B), he offers this concept through the consideration of good and evil as perfectly interchangeable concepts (Baudrillard, 1990). The “evil twin” or perfect other of society is the society we have created by sieving society into the virtual world. This society not only reflects ourselves and our sociality, but transfers it into absorption. While the base difference between the virtual and the real is that the real is so in every way, and that the virtual is real in almost every way, just not in (some) essential way, Baudrillard sees the virtual as that “*excess of reality*”

*that put an end to reality*" (Baudrillard 66 TVI). He explains this phenomenon, which he refers to as the "*obscenity of a whole culture*" through the metaphor of extreme obesity:

*It is when the body loses its rule and its stage or scene that it reaches this obscene form of obesity. It is when the social body loses its law, its scene and its stakes that it also reached the pure and obscene form we know it to be, its visible and too visible form...the spectral and transparent character of the whole remaining unchanged.* (Baudrillard 78 FS).

The radical transformation of embodied space characterizing obesity parallels the electively amputated or paralyzed body. All of these forms of embodiment are spectacles because they are often viewed as obscene or unthinkable and spatially (the space they consume and the way they fill it) they are other. Spectacles are such because they recall a form of abjection, which may or may not belong exclusively to the unconscious. We are all living in a world where corporeal engagement is no longer essential to perform most tasks: to have relationships, to work, to shop, even to have sex. These lived experiences are readily available cyber. Respondents who feel more engaged and satisfied by their online life have forgone the necessity of a body that functions ideally, and the "scene" and "stakes" correspondingly alter. The virtual world as an entity that is more real than reality itself supports the notion of meme rising out of our consumption of communication. I have asked all participants about their particular relationship with the internet and the effects of its networking capabilities on their lives and especially their experience of illness. Though most have denied that the internet had a role in *forming* their desire, they

all admit to its *development* of their desire. As Sean describes:

*... "Around that time, I went on the internet for the first time, and that was a complete, total and utter revelation. I started looking for information about legbraces, and wheelchairs. Somehow, I came across Sue, who was the very first person I knew to share my need for paralysis. To discover that I wasn't the only one elicited a feeling of freedom, of lightness, and somehow of validation. I was a freak, ok, but I wasn't the only freak! I found more people like me, though the other "wannabes" I knew of mostly desired amputation(s). I found a community of amputees and devotees, and was able to speak about all these feelings freely. It was very therapeutic. It helped me accept the fact that I was transabled. It helped me shed guilt and shame. I started a website...I shared my thoughts, feelings, experiences as they related to BIID. Through the website, I was able to meet many others who felt like me. It was good to be able to talk about it all. It allowed me a greater understanding of myself, and of the condition. It also helped me to know I was able to help others".*

There are gross forms of nurtured difference which crop up in all societies (e.g. the obese body, the anorexic body). These forms of embodiment may be representative of the utter elimination of real difference through our surrender to cyber culture. Taking up much space through a morbidly obese physique, or less through a voluntary amputation are both alarming trends in contemporary society. They involve transforming embodiment from the root, and reek of something entirely unsettling about the way we are. Baudrillard's theory may be a finger on the pulse.

**Butler:**

If it seems unlikely to look to Baudrillard and Kristeva in the same breath, it may seem doubly incongruent to include Judith Butler. Butler's criticism of Kristeva was fodder for her work in *Gender Trouble*, in which she accuses

Kristeva of having reproduced the same paternal law she seeks to subordinate through her heterogeneity and female essentialism that calls for maternity as the primer for identity:

*“The repression of the feminine does not require that the agent of oppression and the object of repression be ontologically distinct. Indeed, repression may be understood to produce the object that it comes to deny” (Butler 126 GT).*

However, inasmuch as I lean towards Kristeva for the analysis of my interviews, the overall topic of embodiment troubles is one wholly indebted to the invaluable work of Butler on *Gender Trouble* and *Bodies That Matter*. Butler’s project is to show us that discourse creates bodies; that they are subject to a deeply entrenched political historicity that identifies them. This is not a process contingent on biology and the human necessity for reproduction, though these facts have been convincing material for the promotion of sex as a categorical imperative insistent on few spaces for contesting identities.

Butler asserts that there are only certain types of bodies that we want, that there are only particular bodies within the approved social- political realm of desire, and that these bodies lie on some spectrum of normalcy or reflect an approved standard of embodied subjectivity. For my informants, embodiment troubles arise when the desired body not only does not match, but refutes these standards and, moreover, contradicts the construction of health from the most drastic and basic philosophical level of embodiment: to be physically whole, and to perceive that one should exercise choice in that matter.

The orders of valued bodies, normative bodies, *Bodies That Matter* are officially regulated through the medical system, DSM and surgical approval. The official inclusion of particular bodies is not removed from feminist or any other social prerogative of what is allowed to exist. However, as with my anonymous informant who performs unsanctioned "body mod" operations, there are professionals who deviate from this spectrum, who aid in creating a more complex and changing gender and ability spectrum. The genealogy of normalizing bodies and sexualities which assert a particular formulation of bodies that are allowed to be desirable does not include abject embodiments: transsexual or ambiguous bodies, disabled bodies or obese bodies which have not been regulated for desire. If you do desire (to an obsessive capacity, symbolically, or even openly) an embodiment that falls outside this agreement, as your own embodiment or some other's embodiment, it is official consented upon that you have a perversion, a fetish, a paraphilia, a disorder, or at the very least something to be made into hilarity and pornography.

The possibility of being desired as a disabled person comes down to a very frank statement made recently (July, 2008) in a "nationally representative" poll commissioned by Disaboom (a disability community website): Over 52% of Americans would rather die than be severely disabled. Here we have the medical and social model collide; how bad disability is in reality versus our social perception of disability. We must desire somebody in spite of the fact that they are disabled; this cannot be the reason for desiring somebody. I wonder, can it be a part of desiring somebody? Must the difference hinge on sexuality? Claire



uses this notion as a defense of her attraction to disabled people: *"If it is dirty and horrible and disgusting to be attracted to someone with a disability what does it say about that person with the disability- does that mean that they are dirty and disgusting and horrible too?"*

The internet has dramatically transformed the way we experience repression, allowing for groups who have fallen through the social triage *du jour* to gather on some level: to connect, share and inspire. What that collective might seem to brew (desire for disabled forms of embodiment) was in existence prior to the dramatic transformations of this technocentric era: whether the problem has become amplified or plainly revealed does not negate the existence of the problem. Therein lays the possibility that severe embodiment troubles have somatic origins. I do not want to dispose of this possibility, nor do I want my readers to automatically refute the possibility, though it does not seem likely. There is a high probability that these troubles are social-psychological phenomena. As a social problem, growth of apparently recent membership to having BIID is reflective of the particular social conditions that paint our everyday worlds. These conditions include disengagement with physical activity and the abundance of time spent online as well as the phantasmagorical way of speaking and thinking about our bodies. On the other hand they also indicate an important resistance to traditions of corporeal desirability.

Though we fracture our identities into all sorts of schizophrenic divides, wholeness is seen as the ultimate achievement in a culture still terrorized by

Cartesian dualism. Individuals who drastically alter borders of identity redirect desires which have emerge from corporeal forms:

*If to assume a sexed position is to identify with a position marked out within the symbolic domain, and if to identify involves fantasizing the possibility of approximating that symbolic site, then the heterosexist constraint that compels the assumption of sex operates through the regulation of phantasmatic identification. The oedipal scenario depends for its livelihood on the threatening power of its threat, on the resistance to identification with masculine feminization and feminine phallicization. But what happens if the law that deploys the spectral figure of abject homosexuality as a threat becomes in itself an inadvertent site of eroticization? (96-7 BTM)*

What might happen are creations of new sexual identities and what might be considered positive reinterpretations of the phallogentric model. Some consider these new interpretations horrifyingly aggressive, a literal fracturing of embodiment to sit well in a schizoid society where fantasy has always been constructed upon a prohibition: prohibition bore desire and desire as the possibility to act for said prohibitive bodies.

In psychoanalysis, identity as an essence not contingent on the threat of paternal law becomes an impossibility. Kristeva refutes this principle by supporting the pre-existence of the maternal form, positing that the female identity is not of a lack, but the origin of the symbolic order. Butler contends that it is through its reformation of the same necessity that Kristeva's reformulation sets to refute (the Big Other), that reorganizes the paternal law in a self-same fashion, doing no progress for the emergence of subordinate possibilities for identities outside heterogeneity. Butler's radical democratic project for identity/sexuality

calls for identity to work as a "site of permanent political contest" (Butler 222

*BTM*) whereby:

*If subversion is possible, it will be a subversion from within the terms of the law, through the possibilities that emerge when the law turns against itself and spawns unexpected permutations of itself. The culturally constructed body will then be liberated, neither to its "natural" past, nor to its original pleasures, but to an open future of cultural possibilities. (127 GT)*

I wonder then, what identities are intended to be included in her project?

She names feminized males and phallicized females, but for whom else is this democratization palpable? Would she concur that the identity trouble qualifying the GID experience deserves the comparison to BIID? To paraphrase Butler (97 *BTM*): Does the refusal to concur with the abjection of (disability) necessitate a critical rethinking of the psychoanalytic economy of (desire)? If the identity project "interrogate(s) the exclusions by which it (sex) proceeds" (*ibid*), does disability, which is always contingent upon signifying the exclusion of ability in the definition of particular bodies, parallel sex. To propose the use of the term embodiment troubles rather than disability might be the type of subversion Butler calls for, but who else would she extend this challenge to: the "naturally" disabled claiming ownership for their form(s), or those who desire elective, more than symbolic mutations? I posit this question because it is unclear who her identity project will be open to: there is a real absence of bodies within these texts (*Gender Trouble, Bodies That Matter*), though there is evidence within the text that she sees LGBT (lesbian, bisexual, gay, transsexual/gender) bodies/performances as making

headway in this direction, what for the ability spectrum and the body modification sub-culture?. Butler articulates the horrors of consistent exclusion of homogenous sexual identities, particularly of lesbians, through their slotting into the psychotic and neurotic realm, but are there other bodies which will always remain outside the borders of what matters?

Perhaps, just as Butler asserts, our physical bodies are not attached to an essence, but to a *performance* and the pretending of some who identify as having BIID is just as real as the fully functioning body they were born with. People with BIID might have envisioned a body that will force them to assume a non-sexual identity (a nullified genital libido), an identity which is symbolic of the subordinate, the fear of being castrated, and the fear of not being castrated. As Butler reveals, "*the radical unthinkability of desiring otherwise*" (96 *BTM*) is what bodies marked by disability show us.

### **Embodiment Deficits:**

Another theoretical tool useful for conceptualizing a social study of embodiment troubles is the notion of "embodiment deficit". While amputation and paralysis indicate a literal, physical deficit, Greg Niemeyer coined the term to describe a much more widely shared human experience: .

*"The capacity of humans to extend their bodies to include technically mediated experiences may be limited. A person may reach such a limit, as the amount of bodily experiences exceeds the amount of mediated, embodied experiences. The embodiment deficit is one possible result of that state. A person may seek any kind of physical experience to compensate for an embodiment deficit, including playful, intense physical experiences without any particular purpose... Another outcome of excessive media experience may be self-alienation."*

Cravings for intense physical experiences would predictably be for ones which are stimulating and active, involving physical work. Those with more radical embodiment troubles present another side to this problem; compulsion for the intense and radical experience of paralysis, amputation, using a wheelchair, or another. While this seems to be on the opposite pole to what Neimeyer suggests, their desires may be considered severe culminations of embodiment deficit combined with another less discernable problem. As dire as their particular cases may be I have found that my participants are not immune to the ebbs and flows within the embodiment deficit spectrum. Here Claire describes some variation in her desire to become paraplegic which constitutes cravings for active physical experiences:

*"It's weird. My body needs to move. I want to go for a long walk and enjoy the spring sunshine... I am craving activity. Not in my chair. On two legs. Able-bodied. My whole body... The only reason that I can't is that I have painted myself into this corner. I did it on purpose because I needed NOT to use my legs. I needed to have no choice in the matter. Needed to need my chair. I still need my chair. I still need to not be able to walk. But my body is SCREAMING to move. It's created an awful dichotomy in which my BIID is at war with other basic instincts... My BIID is what it is. This is what it is. It's a war between my mind and my body and this is just one more manifestation of it."*

As mentioned, I offer an extension of the term embodiment deficit to encompass more radical negotiations of embodiment, whereby embodiment deficit may describe a condition which now plagues much of the social body of cyber cultures. It extends itself to extreme cases in the desire to radically, partially, disembody, where it must be accompanied by other factors (social-

psychological) to result in such extremities. Embodiment deficits also hold a more mild and inclusive grasp, nearer to what Neimeyer intended, which makes its more extreme forms relatable to those of us who suffer only the usual embodiment troubles.

The second form includes the experience of possessing nostalgia for something that seems uncanny, which should not be mistaken for youth, but which last happened to us in our early youth. This sometimes unconscious nostalgia longs for the *before we were* immersed in the subtleties of cyber culture and the possibility for increased connectivity and communication of one's own identity through technological mediums, and especially now through user driven forums (discussion boards, membersites (fringe and mainstream such as MySpace, Facebook, YouTube). We have surrendered some degrees of physical engagement with social life, and this has increased maladies of soul, psyche and physical bodies. I am of the last generation who may possess a (albeit terribly hazy) point of origin for the *nostalgia for physical experiences without a virtual reference point*.

What I mean by this nostalgia is a sort of embodied longing, a desire without a necessary direction, that is somehow transferred into disembodied experiences, i.e. time spent on the internet collecting information. The virtual reference point may be any form of media, whether we are drawing from political, sexual or other content. This is not an experience relegated to my generation, but as people younger than myself come into this world they are emerging in an already omnipotent digital saturation. The stakes are that they may become so

fully immersed in the internet at such a young age they forget alternative methods of socializing to draw from. This is a definite wager because this new way of being human forgets much of what it is to be embodied human subjects, namely the body. My forbearers also experience this connectivity disconnect, many of whom are as internet savvy as my generation or more so, being those who really brought us these new heights of digital connectivity (generation X). If there is a digital divide to be drawn, however increasingly illusive it is becoming both economically and geographically, it may be done so just as convincingly in relation to age. Many older people have escaped the major seduction of the internet, yet are fully subject to its power in their experience of the daily frustrations and resulting anxieties of adapting to a seemingly foreign digital culture, or those resulting from remaining on the fringe of that culture.

As we saturate our psyches with an overflow of information; fractured meaning found through constant internet browsing. A pedagogy particular to the navigation techniques of cyberspace fills us up in a very elusive and unsatisfying way, whereby we may know obscure ins and outs of otherwise inaccessible information, but are increasingly lacking a *je ne sais quoi*, which may be a tradition of lived experience, an engagement with the access of information. Without implying a conspiratorial or overly negative lean, it is important to my work to consider how the internet has altered our human experiences. It is impossible to weigh the balance between benefits and detriments, but I tend towards a somewhat pessimistic approach because of the pervasiveness of evidence I encounter in my daily life. I have seen the internet dramatically

transform our interactions on an unprecedentedly massive scale and these kinds of changes are obviously not neutral, yet I cannot help but remark on the possible consequences of such drastic transformations of the social. We are collectively disengaged from the reality of our bodies. There is a new kind of crisis of identity happening, resulting in our being more restless, where people find themselves in liquid, temporary relationships, living very much in digital photographs, and craving stimulating experiences. Very few already mediated reactions are not subject to a proliferation of several layers of mediation. This saturation further separates the experiential stimulus from our embodiment . An example of what I am referring to can be found at any concert: observe the crowd watching the giant screens through the little blue screens of their digital recording devices. Where is the guttural engagement with the music, where are the eyeballs, where are the ear drums? This illustrates how we disembodiment even through embodied experiences.

I do lament a time that is running through my fingers like sands, where the choices people made had consequences that were not moderated by a non-human actor that acts with as much authority as the complex workings of the internet. My informants spend a particularly significant amount of time online accessing information about their condition and participating in relationships, conversations, and debates, especially with others who share their trouble. This is an action almost always defended by participants. I asked Claire whether her time spent online makes her more or less fully available for time spent with her family and friends:



*"It's hard because some days it (going online) helps and some days it doesn't help. At first it felt like it really helped, to know there were others and I can't imagine cutting myself off from that community...I've gotten so many emails from people that say things like, 'I can't believe I'm not the only one, I'm so glad you're out there'...I'm not sure if I want it to go back to the way it was or not, because before my mind was always somewhere else, like there was hardly any peace. Now I can go and focus on that (being online on BIID related forums), I can use my chair and there is a lot of time I'm not focusing on that. I can help people I can have one on one conversation. I feel like I'm helping to further knowledge and understanding about BIID...and so, if I were to get rid of my chair and shut off my contact with the community it would all just be up here again (taps head)...In some ways its kind of 6 one way , half dozen of the other and I'm not willing to go back...I'm a bit of an internet addict, if I could control that and still be online helping people..in a way my activities online, if I could control that I would be much better off. It is really hard to have a balance."*

Taking Neimeyer's definition and elaborating upon the seed idea by approaching embodiment deficit through a broader philosophical spectrum allows for the specificity of analysing various examples, for pairing a comprehensive term with the possibility for an evolving approach for epidemiology in sociology in relation to *meme* in its formation of mood disorders, somatoform disorders, identity problems and paraphilias within cyber cultures, and how they intersect with real physical embodiments such as the actual body modifications discussed here, as well as more common physical ailments like carpal tunnel syndrome (Ashton, 2008).

## **(In)conclusions:**

While First's pioneering study on BIID included only those who desire amputations, his follow-up study encompasses people who 'need' various disabilities. The question as to whether these will result in further distinction within the realm of people desiring disabilities remains unseen, as does the level of their possibility for inclusion in pending volumes of the DSM. The motivation towards diagnostic classification is one that is of ethical concern, and therefore multi-faceted. There remains the idea of the mad scientist; he who wants fame regardless of notoriety, or he who is motivated by gain; the scientist diocese under the multi-billion dollar church of pharmaceuticals that do major business treating new illness. There also hovers the humanist research imperative driven by the desire to help people suffer *less*. After speaking at length with BIID sufferers, I cannot help but imagine that the conversations First and others have had with BID and BIID patients has been a driver in advocating for more research and for treatment options. In our already salient psychopharmaceutical culture, the option of surgery appears to be the most controversial.

My interview subjects have either undergone their ideal body image realization without the assistance of surgeons or have been *pretending* for years. They have all sought psychiatric help, have all been diagnosed at one point with depression (none with psychosis), have experimented with rounds of antidepressants (SSRIs) and combination therapies, and surely fit into any pending plans for surgical eligibility as outlined by the BIID Organization (2003). To date, none have been able to solicit the assistance of a neurological or plastic

surgeon, and elective procedures to become disabled are still illegal, though would be naïve to imagine that they are impossible to get. The example of Falkirk stands as a testament to the possibility for surgery: Falkirk is the hospital in Scotland where BIID advocate Dr. Robert Smith performed a series of amputations for patients who he identified as suffering from Amputee Identity Disorder in the late 1990's, he was then barred from practice. This is the only example of an "official" center where voluntary demand amputations have been administered.

It does not necessarily indicate that one is taking the cautionary perspective when one hesitates over the inclusion of BIID in the DSM V, but we must consider both risk and benefit. Categorization may aid in identifying people who suffer this psychologically torturous impairment, but I cannot help but believe it will also work as a recruitment tool, spinning the troubled desires of some confused people into the nebulous terrain of such a new problem. Still, what lies in store for sufferers of BIID, what would have to change in order to enable them to find surgical solutions to their problem? Claire posits a dire scenario:

*"The only thing that I think could change people's minds if the self-injury problem became so great that they say that they had to do something. I mean, that's why they legalized abortion...in the meantime people are living with horrible mental stress...I've seen 3 three mental health professionals and none of them have ever heard of BIID and when one looked it up they said 'that's too marginal'."*

Queer activist Leslie Feinberg (1998) writes, "*My right to be me is tied with a thousand threads to your right to be you*" (101). Ought we assert the right to self-determined embodiment in the individual capacities we see fit only to deny

that right for another person, however much we may fear the direction of the embodied subjectivity they desire? Is “*that grotesque form of obesity*” discussed by Baudrillard (1990) a much more radical example of the negotiation of embodied space than amputation? While these questions are provocative, I do not necessarily think they can be answered. Still, I cannot remain silent or unaffected by the cybercultural wasteland I regard as heavily implicated in these phenomena through which people suffer such exquisite embodiment difficulties. Limits over our rights to determine our embodiment may be broad, but are still susceptible to a level of official control and legislation, the ethics of which is a complicated issue. We failingly advocate human rights while denying complete individual rights over our own embodiment; where should human rights begin and who should be allowed to determine them?

I know that the burden of this problem is more tremendous than I can begin to grasp for those suffering from BIID, that they would live any other possible way if they were able, but see the realization of their ‘true’ body image as the only solution. In the words of Sean, “I need to be a paraplegic. This simple statement cannot begin to describe the depth of despair and anguish this need creates”. Suicide attempts, fear, ‘pretending’, isolation and depression has marked the life of Sean and so many others who suffer from this very bizarre, relatively unknown condition. When I speak with Sean, Claire, Adam and others I am compelled by their objective analytic capacities and sincerity. They may have found communities which they belong to online, but they make a convincing case for having felt the onset of their desires/needs at a much earlier date.

As random as this condition may seem, we should remain compassionate towards those affected, and open to debate over the philosophical questions that seem to turn these people into abject antagonists, not only because we cannot truly understand it, but because they are genuinely suffering. We live in a society laced with maladies, perhaps one that is quite sick in and of itself, but these people suffer a situation so grave and complex we can barely open ourselves up enough to their own articulations to hear what they are saying. Before I had participants agree to be interviewed I was clear that I was not writing to advocate for surgery rights for patients with BIID. Sean had the following response;

*"Fair warning! To reciprocate, while I appreciate this and think it is important in the long run to have such papers, I have to say, I tire of that. I am advocating for surgery as a viable option for us. I have lived in hell for over 35 years, and cannot bear it much longer. I tend to be more enthused and more willing to support people who also push in that direction."*

While a clear answer to the surgery option is ever more problematized the more I speak with BIID patients, I still am not advocating surgery, though I have come to better understand the tendency, and adequately consider that debate. Interview participants speak so many layers of experience; it seems much easier to latch onto a singular aspect of their abjection to find something concrete, comprehensive or plausible to attribute it to. This spawns philosophies whose debates are divided around the rhetoric about the claim that we might possibly solve this problem or bring it into the spectra of sense and sensibility through

biology, neurology, psychology, psychoanalysis, psychiatry, medicalization, business, entertainment, art, sociology, anthropology or whatever other of the various points of entry and adoption, as we all stake a claim in solving the unknowable nature of something so utterly bizarre.

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