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Bastards, Brains, Boobs and Performance: A Retrospective Account

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Bastards, Brains, Boobs and Performance:

A Retrospective Account

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
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Department of Communication
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Joanna Bartell

Abstract

The two essays that comprise this thesis use personal narrative to discuss various aspects of illness, resistance and the body. The first essay uses performance theory to explore the social structures, mandates and restrictions concerning illness. I use the cancer experience to explore the co-creation of self, identity, and modes of being between "performer" and "audience." "Performer," in this case, is the "breast cancer patient," and the "audience" is comprised of the "social others." The second essay explores cyborgization of the body, its painful effects, and associated social and moral values. It also discusses how we create theory and understanding of self through fiction, media and experience.

Introduction

This thesis is comprised of two essays. The general themes and ideas of each essay were derived from different courses that I took in my Masters program in the Department of Communication at USF, and while both essays still maintain the overarching themes of their original forms, they have been significantly changed – nearly completely in the first instance.

As I progressed through my program I found new ways of discussing the issues presented in these essays, and I anticipate that as I progress as a Ph.D. student, academic and social creature, I will continue to discover new and different ways of exploring the theoretical aspects of existing in various social roles. The roles discussed directly in these essays include those of patient, child, parent, social other, individual, incompetent actor, and cyborg; the roles discussed indirectly include those of woman, crazy, and neglectful actor. Both essays follow themes of social propriety and modes of understanding, accepting, and navigating completely foreign situations. During my thesis defense, one of my committee members pointed out that both essays also follow themes of resistance.

Historically, the “patient” is passive, receiving care and, if they are lucky, information from “doctor,” “nurse,” and/or “care giver.” During recent years, the medical model of doctor/patient has shifted and the patient is often an active participant in his/her own care. The social model of “patient,” however, still constructs the patient as a passive non-actor in need of care, guidance and supervision. The first essay uses concepts of performance theory to explore the inconsistencies I experienced of being as “patient” and being seen as “patient.” As “patient,” I viewed myself as an able, active, thoughtful and

consistent social actor. However, viewed as “patient” I was considered needy, incapable, confused and inconsistent – even by those I felt knew me best. I felt a very definite push from social others to fit into a patient model that I was revolted by both because it did not fit who I was and desired to be seen as, and because I disliked the model of patient as passive. I actively tried to subvert the socially restrictive role of “patient” by monitoring my actions and use of language, aiming to change the views and opinions of social others through resistance to the structures in play. On the same token, my essay points to a resistance to the model of resistance; while I abhorred the delineated role of “patient” as passive, needy, weak, and incapable, I desired to assume that role when I felt particularly terrible due to chemotherapy treatments. However, resistance is seen as a homogeneous whole – either you resist the structure or you don't – and it seemed clear to me that I could not resist the delineated role of patient when I felt well then turn around and embrace it when I felt ill.

In the second essay I explore cyborg theory using fiction and personal narrative based on my experiences through multiple surgeries. Themes of resistance can be seen in my treatment of the social ideals of cyborgs as compared to the actual cyborgization of the body. Cyborgs as seen in media and fiction are framed as superhuman entities whose capabilities are enhanced when their flesh is merged with technology. I use various fictive characters – including one from my own imagination – to discuss levels of both physical and mental ability achieved through technological means and/or conditioning. My personal experience with incorporating technology into my body, however, made me physically weaker and mentally drained; instead of scaling walls and completing amazing mental feats, I struggled to open doors, became frustrated by vacuuming and was dazed

by medications used to dull the associated pains.

The following essays are, and will remain, incomplete. They will continue to evolve, to grow and to gain insight as I do, and I can only hope that I don't stop until I've perished.

Chapter 1: Performing Illness

Introduction

In retrospect, I could have explained everything that transpired using performance theory. I would have primarily cited Erving Goffman, Richard Bauman, and Petra Kuppers; I would have noted their insights, their theories of performance, and their brilliant explanations of human action; I would have talked about frames, staging, keying, memesis, poeisis, kinesis and emergence; and I would have discussed it within the framework of social constructionism. In retrospect, of course, everything that transpired appears perfectly logical.

Unfortunately, performance theory did not exist for me until after I was diagnosed with breast cancer and had undergone chemotherapy and extensive surgeries. During that time, especially within the first four months, I grappled with how to make sense of what was happening to me on a social level. I fought against an unseen force that sought to define me as something other than what I believed I was; the struggle to maintain my identity as I saw it and subvert the multiple identities as "patient" was confusing, difficult, emotionally draining and, sometimes, painful.

It was not until October, 2008 -- over a year after I was diagnosed with breast cancer -- that I was introduced to performance theory. Upon reading the two short articles assigned in my Theories and Histories of Communication class, I experienced what Elizabeth Bell calls an "Ah ha!" moment; it explained *everything*. In that moment, it became clear to me why my family, friends, acquaintances and I encountered so much friction in our relationships, why our ideas of how we ought to act varied to such large

degrees, why I failed repeatedly to sway the people in my life to view me the way I viewed myself, and how we finally managed to reach some sense of common understanding.

This essay is inspired by a piece I wrote for a Social Constructions of Reality course I took in my first semester of graduate school. At that time, I was in my second set of chemotherapy treatments, and I was still trying to rationalize how a simple five syllable utterance could so drastically change the way those closest to me thought of me as a person. How could the declaration "you have breast cancer" transform me from me, "Joey B.," to the delineated role of "cancer patient?" While social constructionist theory provided an excellent framework for the development of identity, meanings and relationships within communities, it left me wanting for explanation. When I was introduced to performance theory, I felt like I had found the inner workings that social constructionist theory was lacking; for me, performance theory is where the nuts, bolts, gears and circuits of social being are located.

In this paper I use the cancer experience to explore the co-creation of self, identity, and modes of being between "performer" and "audience." "Performer," in this case, is the "breast cancer patient," and the "audience" is comprised of the "social others," including close family and friends, acquaintances, and total strangers.

Ultimately, my goal on both a personal level throughout my cancer experience and on an academic level regarding this essay can be summed up by the turtle walker as described by Petra Koppers. The turtle walker brings something private into the public sphere, transfers a highly regulated and regimented existence into an unregulated and

unpredictable setting and moves not with the rhythm dictated by the street, but at the pace of the social anomaly.

Private bodies and public stories meet in the performance. Difference leaves its allocated spaces and mixes in the street. Taunts and injuries are the risks that are embraced in order to assert one's individuality, to claim one's space on the pavement.

(Kuppers, 2003)

“You have breast cancer:” What it Really Means

"The world, in truth, is a wedding."

Goffman (1959)

Fifteen days after my 25th birthday, a general surgeon came sweeping into the little examination room I was waiting in and announced, very abruptly, “Look, we need to talk. This isn’t good, this is cancer. You have breast cancer.” Perhaps it was the surgeon's striking resemblance to Lewis Black, both in appearance and mannerism, perhaps it was shock, or perhaps I simply thought that it sounded absurd. In any case, it took every shred of concentration and self control in my body to maintain my composure while the doctor was telling me about breast cancer. When he finally left the room and I thought he was out of earshot, I burst into laughter.

My sister had been sitting quietly in the corner of the room the entire time; she hadn't made a sound. "Don't cry," she said to me with great concern in her voice. That was when I first felt it, the sudden unknowing of me by the people I thought knew me best. Initially, I rationalized that my sister's response was based on how she thought she

would respond in such a situation, and that she was therefore responding in turn. I informed her that I was laughing, but she continued to appear quite worried.

What I did not realize at the time was that upon uttering the words "you have breast cancer," the doctor triggered a very specific social situation encompassing very specific roles. The mechanisms employed in such situations, while seemingly obvious once revealed, are so ingrained, inherent and second nature that, unless directly pointed to, are completely obscured.

A main component in competent social interaction is understanding the current "frame" in which one is acting. Richard Bauman, citing Gregory Bateson, asserts that we can think of a "frame as a defined interpretive context providing guidelines for discriminating between orders of message" (Bauman, 1977). Discussing how "frames" are constructed in social performances, Bauman states,

there is something going on in the communicative interchange which says to the auditor, "interpret what I say in some special sense; do not take it to mean what the words alone, taken literally, would convey." This may lead to the further suggestion that performance sets up, or represents, an interpretive frame within which the messages being communicated are to be understood, and that this frame contrasts with at least one other frame, the literal.

(Bauman, 1977)

The literal meaning of the doctor's utterance "you have breast cancer" is that a cellular mutation occurred within the breast tissue due to some genetic or environmental

factor which altered the behavior of the cell and in turn led to the unregulated growth of abnormal cells that may or may not spread/have spread to other parts of the body. The "special sense" that the message was interpreted in, however, was that my life was being threatened by an invisible force growing within me that I was powerless to stop without the extremely invasive and toxic intervention of modern medicine. The word "cancer," on its own, carries frightening connotations of death and decay, and with its highly advertised persona preceding it, the qualifying word "breast" placed in front of the word "cancer" creates an increased level of fear and anxiety for those directly subjected to the possible consequences of those words.

The manner in which framing is accomplished is called "keying." Bauman, again referencing Bateson, points out that "it is characteristic of communicative interaction that it include a range of explicit or implicit messages which carry instruction on how to interpret the other message(s) being communicated" (Bauman, 1977). Communication about communication is defined by Bateson as metacommunicative; "In Bateson's terms, 'a frame is metacommunicative. Any message, which either explicitly or implicitly defines a frame, *ipso facto* gives the receiver instructions or aids in his attempt to understand the messages included within the frame.' All framing, then, including performance, is accomplished through the employment of culturally conventionalized metacommunication." (Bauman, 1977). "Once upon a time" keys a specific kind of storytelling, while "It was a dark and stormy night" keys another. "All rise" keys a serious and generally undesirable social frame, while "We are gathered here today" keys a social frame of celebration.

Thus, in retrospect, it is quite clear that the pronouncement of the doctor to me and my sister, "you have breast cancer," and my subsequent pronouncement to family and friends "I have breast cancer," was an extremely potent frame invocation. The frame keyed by the statement demanded a serious, sorrowful or desperate attitude by those directly involved. However, in the moment, as the phrase "breast cancer" and all of its connotations and potential consequences were suddenly dumped into my existence, I laughed.

When my sister and I arrived home and I faced my expectant family, I announced in a grand and cheerful fashion, "I have breast cancer," and then laughed again. My father reacted by displaying upset facial expressions and pacing, my mother reacted by buckling at the knees and grabbing onto the chair she was standing next to, and my brother reacted by appearing despondent and becoming completely unresponsive. I recited some of the stuff the doctor said and offered them the handful of booklets and pamphlets the doctor had given me.

A couple hours later I met my boyfriend of five days, Christopher, for dinner. We were sipping on our drinks when he suddenly asked how my doctor appointment went. "It's cancer," I told him matter-of-factly, then laughed. He stared at me for a moment, unblinking, then asked "Are you serious?" I realized that he perceived my laughter as a sign of my inability to effectively play cruel jokes on people. On his cue, I straightened my face, restated my diagnosis in the most solemn voice I could muster, and then held my breath until I was sure I wouldn't laugh again. After all, I reasoned, the guy barely knew me.

Effects of Inconsistency

"A given social front tends to become institutionalized in terms of the abstract stereotyped expectations to which it gives rise, and tends to take on a meaning and stability apart from the specific tasks which happen at the time to be performed in its name. The front becomes a 'collective representation' and a fact in its own right"
(Goffman, 1959)

In the sixteen days following my diagnosis I was the uncoordinated participant in a jolting, fast paced, disjointed and chaotic dance that, for me, is a defining feature of the breast cancer experience. Every day, doctor, and test brought new information, language, decisions, and opinions. I went from one medical office to the next, usually with my mom or sister, and had new vocabulary, concepts and treatment options thrown at me throughout most days. I did my best to process the information, wrote down the things I was unclear about, and asked questions until I simply couldn't think of anything else to ask. It was exhausting.

Early on in those sixteen days I became very aware of the fact that I was acting inconsistently with the way people thought I ought to be acting. Close friends and family spoke to me in gentle tones, avoided sarcasm and said things such as, "It's ok to cry," and "It would probably be good for you to go ahead and break down," directly to me. At first I used the same rationalization that I had with my sister's reaction to my initial laughter; people were treating me in a manner consistent with how they thought they might react in the same situation. I reasoned that the people I was around on an almost daily basis would adjust quickly and that others would adjust over time.

Then I began hearing some friends and family say something to the effect of "I don't think it's sunk in for her yet," when they thought I was out of earshot. It occurred to me that their understanding of me was much different than my understanding of

myself, and I felt angry and disappointed that the people I thought knew me best viewed my reactions as abnormal, incorrect and as some kind of masquerade. They seemed to be expecting me to react to the situation in a manner that was not only inconsistent with the way I was actually reacting, but also to the way that I thought I ought to react.

On the same token, my close friends and family were reacting to the situation inconsistently with the way that I thought they should. I felt that the appropriate response to the “breast cancer” diagnosis was similar to that of discovering that the trajectory of a category four hurricane was set for our town; we needed to gather supplies, prepare for any situation, brace ourselves and hunker down. But cry about what might happen? That was ridiculous. For all we knew, it might change course, lose strength, or dissipate all together.

The schism between how I wanted to treat the situation with how social others thought I ought to treat the situation did not make sense and was irreconcilable to me at the time. Now, two years later, I understand. Bauman says "Fundamentally, performance as a mode of spoken verbal communication consists in the assumption of responsibility to an audience for a display of communicative competence. This competence rests on the knowledge and ability to speak in socially appropriate ways" (Bauman, 1977). Social appropriateness completely eluded me, and I discovered that laughter is not, in fact, always the best medicine. But I continued to insist on laughter and sarcasm well beyond the excuse of "initial shock," causing me to appear communicatively incompetent and thus socially unknowledgeable and unable. Similarly, I viewed those close to me as increasingly communicatively incompetent as

their seeming understanding of me as "Joey B." veered further and further from how I understood myself.

However, as "the breast cancer patient," and because social others felt they shared a similar position in respect to me, I was in effect the performer and they the audience. According to Bauman,

From the point of view of the audience, the act of expression on the part of the performer is thus marked as subject to evaluation for the way it is done, for the relative skill and effectiveness of the performer's display of competence.

(Bauman, 1977)

Because I appeared incompetent concerning my position and appropriate course of action, my varied attempts to sway my audience toward my way of viewing the situation were ineffective.

My apparent incompetence and inability to engage properly within social norms garnered another undesired reaction by those close to me, which was possibly the most difficult thing I had to deal with: my already compromised independence became increasingly threatened as my concerned friends and family encroached further and further into my realm of control. As I saw it, the medical profession had command of my time, and I accepted that; but the cancer was attempting to rip away at my choices and my future and promising an inevitable attack on my physical ability, physical independence and over all health. I combated this by attempting to maintain some kind of control in my out-of-control life by staying in command of my experience; I tried to

maintain "me" as I saw myself, demanded all the information from all the sources I could, and I tried to live life as "normally" as possible. The conditions were out of my control, but at least I was in the captain's seat, and at least I was going steady.

Unfortunately, my mom also wanted the captain's seat, and one day she hopped in the boat and started trying to take the wheel. At that point I felt that not only was my entire concept of independence threatened, but my command of the doctors' attentions also appeared to be up for negotiation. I wanted to be in control of my situation, and so did my mom; I wanted the undivided attention of the physicians, but my mom wanted half; and, if nothing else, I wanted my doctors to know who I was beyond "breast cancer patient," which became increasingly difficult as my mom tried to re-appropriate me as "child."

My family and close friends joked for a long time after my first surgery that I "went in laughing and came out laughing." Waking up from that surgery was a bitch, though. My initial observations were that I was very, very hot, that my chest felt like it was on fire, and that I had been in surgery for five hours. As my fingertips explored the burning region on my chest, I discovered a gauze pad taped over a hard, painful protrusion. It was immediately apparent to me that I had been in surgery for five hours because the cancer spread to my lymph nodes, which meant that I needed chemotherapy. The nurse explained why I felt so hot when she announced that I had a 102 degree temperature, which they remedied almost immediately. Regardless, I was in as good of a mood then as I was right before they put me under.

There was a group of about 11 people in the friends and family waiting area waiting for me to get out of surgery. The surgeon had debriefed them about the

surprising size of the tumor as well as the lymph node involvement and consequential chemotherapy treatments I would need. Thus, as family and friends ventured back in pairs to visit, and I greeted them with a cheerful "Hi! Look, I'm a cyborg!" and referenced my port and all the drains, pumps and wires coming out of me and running through me, they were not surprised, and even laughed.

When we arrived at my parents house that evening I refused to go to bed right away and stayed up chatting for a while. My dad caught me standing on a chair in the bedroom trying to retrieve something out of the closet; he yelled at me as though I were a child caught misbehaving. I laughed, let him help me off the chair, hugged him and told him that I was feeling really good. "Ok," he said, "Just... just let us help you, ok?"

Determination

"We often find that the personal front of the performer is employed not so much because it allows him to present himself as he would like to appear, but because his appearance and manner can do something for a scene of wider scope."

Goffman (1959)

For a week or so after, I felt that the surgery validated my stance on the cancer situation and had managed to put everyone at ease. Unfortunately, this was not the case, and I learned that my misconceptions were due simply to my temporarily diminished mobility. A few days after the pain pump and drains were removed I was at a family gathering with Christopher when I overheard someone say, "I really don't think she's had the chance to let it sink in yet, I really think she's just been too overwhelmed with the doctors and the surgery and all. I don't think she understands what's coming." Despite their hushed tones and fair distance, I heard them loud and clear. In that moment I resolved to make my case for laughter, sarcasm, and personal ability despite the heavy

opposition my stance seemed to be encountering. "They will know me by the time this is over," I decided.

Erving Goffman points out that "there is the popular view that the individual offers his performance and puts on his show 'for the benefit of other people'" (Goffman, 1959). My resolution that day mandated that from that point forward, my speech, actions and behavior be aware of and informed by the people around me and how they were perceiving me, putting me in a position of constant audience analysis. I was thus more or less offering up my performance and putting on a show for social others, although not entirely for their benefit.

When I began chemotherapy on November 5, 2007, exactly one month after my first surgery, I felt absolutely certain that there was no way I could possibly be denying some kind of underlying truth to the situation. As the chemo slow dripped into me and began eroding my veins and waging war against my entire cellular being, every evolutionary instinct that has kept the human species in existence to the present day was screaming inside me, demanding that I rip the IV out directly and find means to a blood transfusion immediately. After that treatment, after sitting in a recliner for four hours, I was exhausted.

Describing what the effects of chemotherapy feel like is extremely difficult because the things one experiences from chemo are different from everything else and thus lack a common vocabulary. Suffice it to say that I felt like I was drunk most of the five months I was on chemo, but in a very uncomfortable, unpleasant way -- almost as though I were simultaneously very drunk and very hung over. Despite my new found existence as a chemoholic, I refused to go to bed when I got home and decided to make

salsa instead. I did it in part because Christopher, who I was living with at that point, was somewhat insistent that I go lay down.

Christopher's friend Randall came to the house after I had started cutting tomatoes. "How you feelin kiddo?" he asked. I smiled and told him I was good. He talked to Christopher for about fifteen minutes while I very slowly and carefully diced tomatoes, onion, garlic, mango and cilantro. When Christopher walked outside to smoke, Randall turned to me and said, "So how are you *really* feeling?"

I laughed. "I think it's about time I went to bed," I told him.

"That's what I thought," he said, laughing. "You're awesome girl. Now give me some of that salsa and get your ass to bed."

And I did.

Keeping Up Appearances

"Walloch references performance and the ability of everyday situations to re-write scripts, to change the scenario in minute ways, re-reading power and agency."

Petra Kuppers (2004)

Goffman states that:

the expressiveness of the individual (and therefore his capacity to give impressions) appears to involve two radically different kinds of sign activity: the expression that he *gives* and the expression that he *gives off*. The first involves verbal symbols or their substitutes which he uses admittedly and solely to convey the information that he and the others are known to attach to these symbols. This is communication in the traditional and narrow sense. The second involves a wide range of action that others can treat as symptomatic of the actor, the expectation

being that the action was performed for reasons other than the information conveyed in this way

(Goffman, 1959)

Goffman goes on to say that, regardless of motive, it is in the individual's interests to influence social others so that their actions coincide with with the individual's plan. "Thus, when an individual appears in the presence of others, there will usually be some reason for him to mobilize his activity so that it will convey an impression to others which it is in his interests to convey" (Goffman, 1959). In the case at hand, my goal was to subvert the delineated role of "breast cancer patient" and maintain my identity as I saw it. It was therefore in my interests to convey an impression of myself as competent, able, accepting, and in control.

Of the two types of communication described above, the expression given off encompasses "the more theatrical and contextual kind, the non-verbal, presumably unintentional kind, whether this communication be purposely engineered or not" (Goffman, 1959). While I was unaware of the theory that had been written on these two types of communication, once I began chemotherapy I quickly came to understand that there was a vast difference between what I said and what people extrapolated from our interactions. As a result, I became acutely aware of the expressions given off, both by myself and others. I paid close attention to the way people spoke and listened to me; I watched the way they moved their body, the way they gripped their glass, the way they tilted their head, the way they breathed (or didn't), the way they looked away and the way their face changed, ever so slightly. I acted based on the expressions given off by social

others, sometimes disregarding their discomfort with the situation and forcefully asserting myself the way I wanted to be seen, and sometimes aiming to make them feel more at ease. The question "How's it going?" was no longer a question about me living my life, but code for "So do you know if you're going to die or not yet?" I made a point of talking about the mundane when asked that question, telling them about a movie I watched or a meal I cooked or something. When they followed it up with, "Oh... I mean how's your health?" I would smile and exclaim cheerfully, "Well, I'm not dead yet!"

On the same token, I closely monitored the expressions I was giving off, trying to imagine how I must appear to others. The first fourteen days were relatively easy because I simply appeared pale and tired. My hair started falling out on Thanksgiving Eve and I unceremoniously shaved my head on Thanksgiving morning, fifteen days after I began chemotherapy. From that point on, the task of managing the expressions given off became increasingly difficult. Eventually my eyebrows and eyelashes fell out as well and my face was pale with dark circles under my dull eyes. As my healthy appearance diminished over time I increased gusto and tried to smile all the time; instead of "really well," or "great," I was "fantastic!" or "excellent!" I made a point of going out when I felt ok so that I would be seen performing "well," and when in the company of family and friends, I avoided engaging in tasks that I knew would be difficult in hopes of reinforcing the image I was trying to portray.

It was no easy task, though. Expressions given off often worked strongly against me. From the very beginning it was difficult to walk in straight lines, and as treatments continued, I often walked into things, completely missed doorways and randomly fell down. Throughout treatment I also found that I would very suddenly need to sit; it did not

matter where I was or what I was doing, I had to sit right there, right then. I knew that I had no control over these expressions given off, and also knew that I was not expected to be "well" while on chemotherapy; however, I did what I could to diminish the clarity and importance of these signs by treating them as silly mishaps or attributing them to something else.

For example, in November, 2007, I was at a busy mall with my siblings. I suddenly needed to sit, and sat on the floor against the wall I was leaning on. My brother pointed to some benches about 30 feet away from us and said, "Do you want to sit over there?" I considered the possible embarrassment I was causing him, contemplated the distance and then told him that I would rather sit there on the floor because the cold tile felt nice against my back. It wasn't a lie, exactly, because the cold did feel nice, but I answered based on the fact that I knew that I would not be able to make it over to the benches without sitting down at least twice and possibly crawling part of the way.

I also did what I could to hide, as much as possible, unfavorable expressions given off. If I was out and found it particularly difficult to walk, I would do what I could to stay seated for as long as possible and, in the event that I had to get up, I would plan my route in such a way that I was always near a wall, post, chair or table that I could use for support if necessary. If I felt nauseated in public I would discretely pop some anti-nausea pills and sit in my car or the bathroom until it passed, and the one and only time I needed my pills but had left them at home because I was feeling "good," I simply got in my vehicle and drove to my parent's house where I knew they had some anti-nausea medicine left over from my surgery. Even when at home with Christopher I would

employ similar strategies, not wanting him to witness my "disabilities" and report them to others.

When I was alone, backstage and out of the view of social others, I took no such precautions. I walked around the house ricocheting from one piece of furniture to the next, walking into walls and falling over randomly. I would laugh at myself and sometimes lay down where ever I happened to land, content to spend periods of time on the kitchen floor in positions that, I thought, should have been uncomfortable. Eventually, when I decided to move for some reason or another, I would often crawl to my next destination, possibly stopping along the way to lay unmoving for a while in a new spot. When I was in the presence of social others, I put an inordinate amount of concentration and effort into completing tasks such as maintaining a straight trajectory, walking from point A to point B without stopping, and not dropping things. Backstage, however, I would drop a plate and then take over an hour to clean it up, stopping repeatedly between points, walking into everything along the route and crawling for at least part of the trip, dragging the broom and dust pan the entire way.

The Detriment of Being Genuine

"Whether an honest performer wishes to convey the truth or whether a dishonest performer wishes to convey a falsehood, both must take care to enliven their performances with appropriate expressions, exclude from their performances expressions that might discredit the impression being fostered, and take care lest the audience impute unintended meanings."

Goffman (1959)

Toward the end of my first set of treatments, I finally began to feel a change in the way I was being perceived. However, by that time, my performance, which started off completely genuine, was no longer honest. I wasn't "fantastic" or "excellent," I felt

terrible: It took me hours to sweep, or vacuum, or mop, or do dishes; I couldn't get through a movie, or a book, or a conversation because I was simply incapable of following it; I couldn't even sleep because of the chemotherapy, steroids and pain. But I stubbornly maintained my performance as best I could for fear of reversing what little competency I had managed to establish.

Discussing misrepresentation in performance by performers who present a false front, Goffman states,

we think of the precarious position in which these performers place themselves, for at any moment in their performance an event may occur to catch them out and baldly contradict what they have openly avowed, bringing them immediate humiliation and sometimes permanent loss of reputation,

(Goffman, 1959)

While Goffman differentiates between blatant, deceitful lies and "white lies," I assert that changing my act mid stride would have resulted in the negation of the authenticity of my entire performance.

While I was unaware of Goffman at all at the time, it seems that I shared his philosophy that

as human beings we are presumably creatures of variable impulse with moods and energies that change from one moment to the next. As characters put on for an audience, however, we must not be subject to ups and downs. As Durkheim

suggested, we do not allow our higher social activity “to follow in the trail of our bodily states, as our sensations and our general bodily consciousness do”

(Goffman, 1959)

The defining moment of my performance came on the morning after the last treatment in my first set of treatments. It was in that moment that I realized how far I was willing to go to maintain my performance and exactly how fraudulent my performance had become:

I woke up with the sun, as I did most mornings when I was on chemo. I surveyed my body, trying to judge how I felt. The doctor prescribed a tri-pack of anti-nausea pills that were to be taken on the day of and two days after my chemotherapy treatments; they were very effective. I could feel that I would not be able to sit up, never mind get out of bed and walk to the bathroom where the pills were.

“Chris,” I said too quietly, then tried again, “Chris...”

“What?” he responded, seemingly irritated.

I did not seem to care, “Will you get my pill?”

He signed loudly and pushed himself out of bed forcefully, causing my body to rock uncomfortably. Seconds later he flopped into the bed heavily, causing me to bounce and rock. “Here,” he demanded laying with his back to me, hand stretched over his shoulder waiting for me to retrieve the pill.

I took it from him and assessed the state of my mouth and throat. Before chemo, I had no problem taking pills without water. Now, though, it was different, and at that

particular moment, my mouth was so dry that I found it difficult to even talk; I knew I would not be able to take the pill without water.

“Chris?” I asked again.

“God damn, what?” he said angrily, rolling slightly toward me for emphasis.

I noted my lack of response to his hostility (emotional or otherwise), concerned only with the objective of not vomiting. “Will you get me some water?” I asked.

He sighed even louder this time, jolting the bed even harder than before. “Here,” he demanded a few seconds later, holding a glass of water over the bed.

I very carefully pushed myself up just enough to take the glass. As soon as it was free from his hand, Chris dropped his heavy body back into the bed, making me bounce once more, except while slightly sitting. I swallowed a small amount of water to make sure it would go down, then took the pill.

“Here,” I offered quietly, holding the glass out. He rolled over and took it from me and put it on his nightstand.

I slowly lowered myself back down on the bed and waited.

My puppy, an adorable Australian Shepherd that my sister and brother-in-law got me in hopes of keeping my spirits up through chemo, barked once, which meant it was 6:58am. Fifteen seconds later, she barked twice. Fifteen seconds after that, she barked twice again, and so on.

“Oh god damn,” Chris said angrily, and then, much like the puppy, repeated himself shortly after.

I reassessed myself and determined that standing at that point would most definitely lead to collapse and vomiting.

The puppy barked with increasing urgency. Chris cursed with increasing irritation. I remained still and silent with no feeling beyond that of the nausea swirling in my head, pulsing hotly through the spine in my neck and into my shoulders, through my jaw and down the back of my throat into my chest.

I felt him roll partly toward me, again for emphasis. “Are you going to take care of your fucking dog?” he demanded.

It was difficult to talk. “In a minute,” I mumbled.

“Oh god damn,” he said again, somehow thrusting himself back onto the bed hard enough to make it shake.

The puppy was quiet briefly. But only briefly.

Once the nausea started to subside, it subsided quickly. I opened my eyes and decided I could stand. I pushed myself up slowly and sat on the edge of the bed, letting my body orient itself to its now vertical position. I slid off the bed onto the floor and stood. I didn't want to stand. I guided myself along the edge of the bed then let go and reached for the dresser, falling forcefully into it and partly on the floor.

Chris sighed loudly in a grumbly kind of way at the disturbance.

I pulled myself up, resolved to make it to the door without Chris actually seeing me fall. I made it to the wall and leaned heavily against it, sliding myself to the door. I opened the door, stepped through, pulled it closed behind me, and collapsed on the floor.

The puppy, her tiny bladder surely ready to burst, looked at me expectantly. I laid on the floor looking back at her. “Hey,” I said quietly. “Good girl.” We stared at each other for a few minutes until I pushed myself into a seated position. The puppy watched as I sat there.

After a couple minutes I decided that I could not stand and proceeded to crawl to the puppy's crate. She was very excited when I let her out, and while the door seemed impossibly far away at a distance of about 15 feet, she needed to go out, so I started to crawl, taking only one break on the way. When I reached the door, I realized that I could not open it from the floor; it was heavy and required a hearty jerking motion to make it open. So I pulled myself up on the couch, gripped the door knob with both hands and jerked it open just enough for the puppy to squeeze through. Closing the door required less force, but still needed a good push, so I let myself fall into it and slid down to the floor.

It was a cold December morning, and the door, which was made of metal, was unpleasantly cold. I sat there in my pajamas, bald head leaning on the metal door, staring at a blanket draped over the back of the couch and thinking about how cold it was where I was sitting. I stayed like that for a while, calculating the distance between me and the blanket (about four feet, I reasoned) and when I finally decided to move, I pulled myself up using the door handle, transferred my weight to the back of the couch and decided that standing was a terrible idea. I pulled the blanket down to the floor with me and crawled over to the wall. I leaned against it, holding the blanket against my stomach, and stared at the empty food and water bowls on the floor. They were impossibly far away.

Tears rolled down my face, but I wasn't sure why. I tried to figure out if I was sad or if my eyes were just watering, but the only thing I felt was cold. I laid down on the carpet, holding the blanket in my arms.

In that moment, lying there on the floor alone, emotionless tears dripping onto the carpet, I finally felt that I was being allowed to operate in the frame I initially wanted; I

was finally being viewed as the independent and capable Joey B. that I was pre-cancer and not simply as “breast cancer patient.”

I felt triumphant; I managed to get out of bed when I could barely stand, let the dog out at the most extreme point of sickness in my life, and not compromise my performance with Chris. But I wanted Chris to get out of bed, walk out the bedroom door and find me there on the floor. I was exhausted from continuing my initially honest performance under what was now a facade of being “fine,” and I wanted him to realize that I was, in fact, quite the opposite. The chemotherapy was quite literally killing me; I could feel it in my skin, my bones and my brain, and I could see it in my dull eyes, pale face and bald body. I wanted someone to carry me back to bed because in that moment, I could no longer carry myself.

Still, I continued on.

Conclusions

*“I’ve had recurring nightmares that I was loved for who I am,
and missed the opportunity to be a better man.”*

Muse (2006)

Elizabeth Bell tells us often that “you must know the rules before you are allowed to break them.” The rules in play here are based on a social theory that, while not necessarily apparent, are put into play and reinforced by all. Theory, such as performance theory and social constructionism, is built on observation, discussion and lived experience, although the word itself often carries a lofty, abstract connotation. However, theory functions as a means of explanation to various social norms, behaviors and changes, so knowing the rules before we break them requires knowing how to explain what we are doing and why.

Never having heard of performance theory, I proceeded with reckless abandon to attempt to defy a theory without knowing the rules. I enacted a particular performance of self without realizing that I was performing; I aimed to elude the frames being thrown at me without any understanding of performative framing; I attempted to reframe personal interaction through keying with absolutely no sense of what those things were or how to properly utilize them. In a sense I was trying to break loose without understanding what was pinning me down -- rebelling without understanding what, exactly, I was rebelling against.

I failed repeatedly to construct my identity the way I saw it in part because I lacked any and all understanding of my position within a predetermined framework created and perpetuated by the mechanisms of social constructionism and social performance. So while I may have maintained a consistent performance throughout, I never acknowledged my expected role within the cancer “genre” yet still attempted to negate it. Furthermore, I was arrogant enough to believe that I, an individual social actor, could establish and maintain a desired identity in the face of vast social opposition.

These instances of trying to break the rules without knowing them, of having very little understanding of the underlying social theory in play, created distress, anger and schisms that were immediately resolved in my “ah ha!” moment upon discovering performance theory.

While I have since gained much insight into the social construction and performance of identities, I was left with just as many questions. As I discussed earlier, while my initial performance was completely honest and genuine, by the end of my first course of chemotherapy my performance was neither genuine nor honest. Rather, it was

forced, difficult and often painful. I felt that changing direction at that point, however, would have compromised my overall authenticity, lending my entire performance to severe scrutiny, so I stayed the course. The personal toll of maintaining the facade caused both physical discomfort and personal doubt regarding my own honesty and integrity. Did the dishonesty that temporarily constituted my social performance render my entire performance inauthentic?

While I have not yet derived the answer to these questions, I do believe that I effectively moved away from the stereotypical “breast cancer patient” model that social norms seem to mandate. Like the turtle walker, I placed a mode of existence in setting where it did not belong, forcing people to look, take note, and, possibly, move at a different pace.

Chapter 2: Cyborgization of the Body

The Bastard Child

When I was an undergraduate at The Honors College in Jupiter, FL, I took a creative writing class. One of our assignments in that class was to create a character and a context for that character to exist in. I created Dorian Maximus.

Dorian was born into a post-nuclear-war world of sparsely vegetated islands that were created through catastrophic explosions and melting polar ice caps. Christianity was king, saturating the people, the buildings, the government, and the law, and the fragmented US was struggling to regain its status as a world power. Dorian was a boy born to and abandoned by a couple who lived in a colony outside of government run society, although patrolled by government police. While married by the standards of their colony, they did not have government sanctioned marriage or reproduction permits. Dorian was thus considered a “bastard child” and posed an imminent threat to his parents. He was found by a scientist and ultimately adopted by the authoritarian government who then engineered Dorian into a kind of perfect being – an experimental perfect weapon.

Dorian did not remember what had happened to him, did not yet know how he was transformed, but he was a smart kid and knew that something was up with the web of scars that decorated his body. Eventually breakthrough memories and classified documents helped Dorian regain bits and pieces of his memory, but “what happened” would remain a foggy concept to him throughout his life. The reader, on the other hand, would be presented with a much clearer understanding of Dorian's past; the reader would know that Dorian had undergone a series of experimental, revolutionary surgeries that, in

short, caused a kind of titanium mesh membrane to form over his bones, veins and organs, turning him into an almost indestructible creature. He was brilliant, very well educated, and chillingly even tempered.

A few years later, through books and movies, I discovered that Dorian was a hybrid of Robert Ludlum's Jason Bourne and William Gibson's bio-engineered cast of characters in *Neuromancer*. Dorian was superhuman; like Jason Bourne, his intelligence, understanding and physical abilities were far superior to those of other humans, and similar to Gibson's characters, his titanium mesh fortifications turned his vulnerable human form into a much more powerful entity.

After that semester, I put Dorian in a three ring binder and stored him on a book shelf, then in my closet, then in a box at my parents' house. I didn't think about him for years, and I still have not taken his original character sketch out of that box, but on October 5, 2007, Dorian resurfaced.

Something Other

When I woke up, I was acutely aware of three things: time, temperature, and pain. "I'm *so* hot. Is it really 4:30? Why is my chest on fire?" I asked the nurse in rapid fire style questioning. I had gone into surgery at 11am to have a lump removed from my breast, which, the doctor said, would not be a long surgery. My hand reached up to touch the burning in my chest, my fingers gliding over smooth skin, over the fire and onto an unnatural protrusion. The nurse told me that it was indeed 4:30 and announced that I had a 102.3 degree fever. She continued, informing me that the burning sensation I was experiencing was from the port. I immediately understood what that meant and why I had

been in surgery for so long; the cancer had spread, so my doctor removed my lymph nodes and put the port in so that my now necessary chemotherapy treatments would not destroy my veins.

As I began taking note of the rest of my body, I discovered a set of thick tubes draining excess fluid sewn into the surgery sites and a thinner set of tubes attached to a “pain pump” that delivered a local anesthetic. The tubes and fluid receptacles all hung around my body, tugging uncomfortably on my skin if left to dangle; the pain pump, filled with a certain amount of local anesthetic, looked like a black canvas purse with little tubes leading from it to under my shirt somewhere. As I touched the area above the gauze on my chest, I felt a small but pronounced tube running from the port to somewhere under my collar bone. The tube was barely noticeable to the eye, but unmistakable to the touch.

I immediately thought of Dorian. I fingered the tube under my skin, thinking about Dorian's veins. I decided that Dorian's reinforced innards would not be so palpable, and as I looked to my sides at the wires, tubes, drains and pumps hanging about me, I concluded that I was some kind of inside out cyborg and not Dorian at all.

Later that night, unable to sleep, I wrote an email to my close friends and family detailing Bob’s¹ extraction from my breast, telling the recipients that while I was sleeping the doctors had installed tubes, drains, wires and a port, leaving me looking like some kind of inefficiently built robot and transforming me from my simply human state into a cyborg. I conveyed the pain and immediate attention that this transformation demands, noting my three waking observations and describing my new, inhuman feel and

¹ Bob was what I named my cancer. At first it was meant to be the name of the primary tumor, but when we found that the cancer had spread, I generally referred to it as “Bob and his minions.”

appearance.

The installation of that device signified my personal entrance into a world of physically and mentally altering surgeries, pills and chemical cocktails that would change me all the way down to my cellular being. It was not exciting, romantic or enticing like Dorian's life and story were; Dorian's scars made him ready for battle, for life, while mine were from surgeries to preserve my life, and instead of becoming super-human, I became sub-human; function and ability taken away instead of added.

Rubbing my fingers along the tube that leads from my port to somewhere under my collar bone became a bad habit, and every time I traced that meandering line, I imagined it was an indestructible vein that has been modified with titanium mesh by my doctors to keep the chemotherapy and other drugs from eroding my body. But it was only plastic tubing – destructible, unnatural, temporary – and it only reached as far as the nearest artery, preventing my fragile veins from hardening, but allowing the harsh chemicals to take full effect.

Since that October evening in 2007, when I officially dubbed myself a cyborg, I have undergone various chemical therapies, swallowed countless pills, received over 60 shots, been operated on three times, had tissue expanders and two additional ports installed, and distorted my body in ways it was never meant to be changed. Throughout the duration, I have been advised repeatedly to stay positive and keep a good attitude – mind over matter, right? For the spectators of this dangerous game, perhaps; maybe it is important to them for the afflicted person to remain in good spirits so that they do not have to consider their own mortality. However, for the breast cancer patient, the mind/body dichotomy is erased and the lines between human and machine blur and

tangle as they feel and see themselves being transformed from their simply human state into something else.

Our Techno Selves

Donna Haraway suggests that the organic human does not actually exist and that we are all, in fact, post-human. Our lives are saturated by technology – the food we eat, the clothes we wear, our shelter and even the way we think. Furthermore, the concept of “natural” itself is not without technology. Rather, it is a myth that we have created for ourselves that denotes "comfortable old hierarchical dominations" (Haraway, 1990), meaning that what we consider our “comfort zone” is translated into being “natural.” Everything else – everything new, up and coming – represents "scary new networks"(Haraway, 1990) that have not yet had time to seep into our lives to the point of seeming “natural.”

Similarly, Craig Klugman argues that mankind’s creation of technology has been a product of our mechanical minds; not just computers and other high tech instruments that we have devised, but simpler tools that have proved to be innovative solutions to various problems throughout the ages. Stone arrows, obsidian blades, wooden stakes, clay bowls, stone buildings, paved roads, and various art forms all point to their creators' ability to adapt to and use their environments while simultaneously displaying the spectrum of human behavior: carved wood can be used for sports, killing animals, hurting people or creating art. Modern day tools including vehicles of transportation, electricity, cellphones and internet devices have moved beyond simple adaptation to and use of environment; for a majority of the world's population, it is both how we navigate and

experience not only interpersonal relationships, but also every environment we cross into. Clearly, technology has been an integral part of us for tens of thousands of years – a manifestation of our subconscious – so the claim that we are merging with technology into machine integrated creatures is not an innovative idea: it is who we are.

Vargas and Meyer argue in their article “Re-signification of the Human in the Context of the ‘Cyborgzation’: A Look at the Human Being-Machine Relationship in Intensive Care” that because intensive care nurses are constantly exposed to technology they internalize it and thus transform from human to cyborg. The nurses do not have technology implanted into their physical bodies, however, they internalize the technology around them to such a degree that it becomes part of their subconscious. While Vargas and Meyer use Haraway’s model of the cyborg as a machine/human hybrid, they postulate that the intensive care nurses must undergo a process of technology embodiment through their work to achieve cyborgzation rather than being considered the “post-human,” technology infused creatures of Haraway and Klugman’s essays.

But these ideas of externalizing our own mechanical minds and internalizing the technology that we create can be taken further. According to Haraway and Klugman we are technologically minded animals capable of creating things to fulfill our needs; at the same time, however, that technology is an extension of ourselves. Our bodies can be fitted with many different tools: A spear works as an extension of our arm, allowing us to reach across greater distances while at the same time making the act of killing much easier and more efficient; a power drill, also an extension of the arm, allows us to do things that our hands, on their own, would have a very hard time doing; a stool or a ladder extends our legs, allowing us to reach heights that we may not have been able to

reach without them. We keep our technology on our bodies and rarely leave home without it, shoes allowing us to cross terrain with greater efficiency, shirts, pants and jackets allowing us to exist in places that our naked bodies would freeze. We naturalize all of these external technologies, and they become part of us much in the same way that Vargas and Meyer argue that the technology in intensive care wards becomes part of the nurses. But those technologies – the clothes, cars, phones and drills – are external to the human body; what happens when we physically put technology in our bodies? Does it become part of us? Do we become part of it? Are we somehow *different* with technology inside of us – less human – or are we simply bringing it back home?

The creative imaginations of technologically minded post-humans have been grappling with these kinds of questions for years, weaving fascinating, exotic, futuristic adventures that sometimes turn out to be very good predictions of what is to come. Stories that have captivated our minds and imaginations include *Frankenstein*, *Bladerunner*, *Crash*, *The Terminator* series, *The Bourne* series (*The Bourne Identity*, *The Bourne Supremacy* and *The Bourne Ultimatum*) and *Neuromancer*. The authors of all of these stories were toying with our fascination with technology, speculating about what the future might hold, wondering how the human race will shape itself, and guessing how it will react to its own creations. In *The Terminator* and *Bladerunner* the humanity of machines and heartlessness of humans was discussed; in *The Bourne* series the mechanical nature and inhumanity of humans was highlighted; in *Frankenstein*, *Bladerunner*, and *The Bourne* series, humans' fear of what they themselves created is put in the spotlight. Donna Haraway's work spoke to those thoughts and fears just as much as they spoke back, confirming and re-evaluating one another as the landscape changed and

evolved until, finally, the ideas set forth in each of these works seemed less scary and more, well, natural.

It follows, then, that the incorporation of technology into our bodies – fake limbs, other people’s organs, laser surgery for corrected vision, rods and steel plates to replace bones, screws to hold our broken selves together – should seem quite normal.

Unfortunately, however, our bodies tell us that this is not the case. Rather, our bodies often react to foreign parts being incorporated into them quite badly, giving us infections, fevers and failures to accompany large amounts of pain as they attempt to attack and dismantle the technology we so crudely introduce. But those pains and side effects are rarely discussed in our imaginative wanderings through sci-fi landscapes, making the transformations necessary to attain a level of cyborgzation that incorporates machines into ourselves seem not only completely realistic and even desirable, but lacking painful consequences.

Cyborgs, Bodies and Brains

William Gibson’s *Neuromancer* was ahead of its time, introducing the concept of cyberspace before technology had dreamed of it; but his ideas were not limited to cyberspace as we understand it today. Rather, humans themselves were biologically engineerable machines integrated into the vast landscape of technology, capable of being upgraded, accessed and plugged in; cyberspace was a world unto its own, a place where the body was more or less abandoned – although not entirely. Gibson brings his readers into a world of fusion, blurring and erasing distinct lines between human/machine, mind/matter and consciousness/unconsciousness. In *Neuromancer*, such distinct

separations between these concepts simply does not make sense; many characters in the book are physically enhanced by upgradable technological devices implanted in their bodies, allowing them increased physical ability. Some characters, such as the main character, Case, have the ability to “jack in” to cyberspace – an ability that not all humans have. These people are called “cowboys,” and some are highly adept at navigating computer systems, entering cyberspace by connecting themselves to consoles using electrodes and creating programs that allow them to hack into various systems. Case is one of the very best cowboys – so good, in fact, that he is sought after both as a target and for hire. While the entrance to cyberspace seems like a purely mental activity, cowboys experience physical sensations of rising, falling, smell, taste, touch and vision; they can even die.

In Gibson’s world, cowboys like Case loathe the flesh and the needs associated with the human body, desiring to be all mind without matter. There have been many times when, feeling completely alienated by/from my body, I, too would have preferred to transcend matter and exist solely in my mind; but as I sat on the floor staring out my living room window early one morning – bald, dazed, eating a chemo induced breakfast of chocolate peanut butter ice cream and contemplating my mortality – I briefly considered the mind/body dichotomy and had myself a good laugh. How, I wondered to myself, could anyone possibly believe that we can overcome the bodies that sustain our minds? How could we ignore the way mind and body grow together, work together, and erode together? Chemotherapy destroyed blood cells, liver cells, skin cells and hopefully cancer cells, but it also destroyed brain cells, causing the rapid deterioration of my mental abilities. My memory was shot, my attention span destroyed, and my equilibrium thrown

completely out of whack. It was impossible for me to carry on a conversation or even think complete thoughts, and I regularly walked into walls and randomly fell down. Try as I might, I was unable to rise above my physical being into a state of pure mental existence, my mind as poisoned as my body.

Even in Gibson's sci-fi version of cyberspace and a hyper-technological society, it is not possible to sustain mind without body, nor is it truly desirable. Gibson highlights the undesirability of separating mind from body using the construct "Flatline." The Flatline is a "hardwired ROM cassette replicating a dead man's skills, obsessions and knee-jerk responses," (Gibson, 1984). The construct is of an infamous cowboy, McCoy Pauley, or Dixie, that had survived brain death – had "flatlined" – several times, but ended up dying of heart failure in the end. As Case's mentor, Dixie had once told Case that he refused to have the surplus Russian heart that had been implanted in a POW camp replaced because, he said, he needed it's "particular beat to maintain his sense of timing" (Gibson, 1984). Case and his partner Molly broke into the library where the construct was stored after Dixie's death to steal it with the intention of using it to help them with a much larger, more difficult project. Unequipped with its own memory, Case plugged the Flatline construct into the "bank" (a computer of sorts) he was using and gave the construct real time memory. When Case returned to his computer a day later, the Flatline announced to Case that he has spent enough time jacked into the computer to realize that he is dead and asked, "Do me a favor, boy. [...] This scam of yours, when it's over, you erase this goddam thing," (Gibson, 1984). In other words, as mind only, we are little more than computers. One of the artificial intelligences in *Neuromancer*, Wintermute, makes this analogy when commenting on how difficult it is to work with humans because of

their unpredictability. On the other hand, constructs like the Flatline are easy to work with because they are predictable, pure ROM, and easy to follow – although, it would seem, incomplete.

It may be possible to record “mind” and create a construct that can be saved and accessed when convenient, but it is not possible to separate mind and body without permanently severing the two – without killing the person. Case, despite the fact that he is jacked in to cyberspace, still maintains corporeal sensations of height, depth, taste, smell, ascension, descending, speed and size; and while cyberspace may provide some relief from the physical world, the effects of that world can still be felt by him even though he is theoretically removed from his body.

It isn't just his physical need to eat, sleep and excrete that keeps his mind and body inextricably linked, though, and this becomes especially apparent in Case's most dramatic, lengthy death scene. The AI called Neuromancer – Wintermute's counterpart – hijacks Case's consciousness while he is in the matrix and plunges him into a kind of dream-world constructed by the AI from the memory of its creator. Case feels, tastes and smells in this dream-world, living there in a bunker on the beach with his dead ex-girlfriend and understanding that it is not quite real, although his memory of himself and where he came from is muted. On the third day in this dream-world, Case wakes up to the sound of a faint beat and begins to see transparent hieroglyphic patterns streaming across the floor and walls. He goes looking for Neuromancer, who in this dream-world appears as a Brazilian boy. He finds the AI and while talking to him on the beach, the patterns become brighter and more pressing and the music becomes louder. Neuromancer tells Case, “Stay. If your woman is a ghost, she doesn't know it. Neither will you” (Gibson,

244). Referring to the hieroglyphics and beat of the music, Case tells the AI that his world is breaking down, that the virus that Case and the Flatline set loose is cracking his defenses. Neuromancer responds, “No. [...] It is more simple than that. But the choice is yours” (Gibson, 1984). Case “turned and walked away, and after the seventh step, he’d closed his eyes, watching the music define itself at the center of things,” [...] “He walked on, following the music. Maelcum’s Zion dub” (Gibson, 1984).

When Case wakes up in the “real world” he finds that his partner, Maelcum, has given him a double dose of an extremely strong upper that Case had in his pocket and had put his headphones on Case and cranked up the volume of his Zion dub, a heavy bass beat music that the Zionites listen to almost constantly. Maelcum tells Case that he had flatlined for maybe five minutes.

Even though Case was dead and his mind had been taken over by an artificial intelligence, he was still attached to his body. Had Maelcum removed the trodes that connected Case to the matrix, mind and body would have been separated and died, one stored as a ROM construct and the other left to decompose. However, the physical world and its trappings had infiltrated Case’s subconscious, even on the verge of permanent death, and restored Case’s mind to his body, allowing them to remain a single, living entity.

Only technical differences separate *Neuromancer’s* reality of mind and body from any other reality of mind and body. For instance, instead of an artificial intelligence putting someone in a coma and providing a dream world for them to live in, perhaps it is a gunshot wound like in *The Sopranos*, and instead of the combination of heavy bass music and an overdose of betaphenethylamine used to bring Case away from permanent

death, it is an unwillingness to relinquish identity and the voices of Tony Soprano's wife and daughter that bring him back from the brink.

As a breast cancer patient, I have come to understand the unbreakable bond of mind and body, though my experiences have been less severe than Case's and Tony's, demonstrating the link with much less drama. However, over time, the experiences proved potent enough that the thought of my mind existing without my body became quite a laughable matter. After the effects of chemotherapy and two lumpectomies, I concluded that the connectedness of mind and body was quite clear to me. However, the only conscious thought that I really gave the concept was when I considered the idea that I could overcome cancer and the related pain with positive thinking – that is, until recently.

Happy Breastless Needles and Interns

On Tuesday, July 29, 2008, I had bilateral mastectomies with reconstruction and came to the following conclusions: 1) Physical pain cannot be overcome with happy thoughts, although it can sometimes be subverted, 2) Embarrassment is an extremely powerful component of consciousness and cannot be overcome or subverted, 3) Experimenting with pain tolerance is a terrible idea, 4) The physical transition from human to mechanical hybrid is extremely painful, and 5) The ability to implant software into my mind that would override my consciousness but allow me to react in a pre-programmed, mechanical manner (like Gibson's character Molly) would be very helpful in situations like this... or would it?

Pre-surgery preparations included a type of spinal block that required four injections on either side of my spine, for a total of eight injections. The general procedure is to stick a needle into marked spots on the back, lightly stab the rib, then angle down so that the needle goes under the rib and pushes up with unnatural force. Once the needle is in, the syringe is changed then liquid is injected. Each stage of the process produces different kinds of extreme discomfort and pain that cause various levels of chair gripping and distorted faces, the most intense on the lower two points of each side.

When the anesthesiologist finished one side and said to the intern accompanying him, “Do you want to do the other side?,” and she replied, “Well I’ve only ever tried it once,” the level of anxious discomfort increased exponentially. “That’s fine,” the anesthesiologist said to her, “you can keep watching me and then do the last two.” The desire to either jump off the table, demand not to be experimented on, or turn off my consciousness were all preferable to having unsteady, uncertain hands jiggling needles in sensitive areas of my back. However, in what I considered an altruistic act, I did not protest, reasoning that she had no other way to learn; then, when she proceeded to cause considerable pain through repeated mistakes, re-tries and poor angling, I smiled somewhere inside, thinking that perhaps I was sparing someone with a lower pain tolerance from the intern’s less than gentle touch. While the pain did not subside at all with these thoughts, I did manage to remain silent by carrying on an internal monologue and convincing myself that I was suffering for the greater good.

After administering some “happy juice” into my IV, the nurse told me that I probably wouldn't remember anything from that point on. However, just like the time before, I remember everything up to the point that they gassed me. When they wheeled

me into the surgery room, they first transferred me from the gurney to the surgery table. The process was slightly embarrassing, as they had to roll me on one side and I was wearing a hospital gown, but they were all women nurses, so it wasn't too bad. Then they needed to put electrodes on my back. When I tried to sit up, I realized that sitting was not an option for me anymore, although at the time I was confused as why. The nurses pulled me up, though, and put the cold electrodes on my back, then laid me back down. There was some concern when it turned out that I did not have a heart beat, but they pulled me back up again (as I apologized for being an inept sitter-upper), replaced the electrodes and then, when I did in fact have a heartbeat, laid me back down and gassed me.

A few hours after I woke up from surgery, I finally had my nausea under control enough that I could get up without serious risk of vomiting, which was good since saline had been dripping into my bloodstream continuously for 10 hours by that point and I felt as though I might burst. So, for the first time that day, I hit the nurse summoning button and two of them appeared to help me to the bathroom. Without ever actually touching me, they walked beside me the whole ten feet from my bed to the bathroom, one pushing the vitals monitoring station I was attached to.

Having just had rather physically altering surgery, I found it quite difficult to move my arms; however, I barely managed to reach my right arm back far enough to hold my gown over myself, which was being held open by all of the wires and tubes that connected the vitals monitoring station to my left arm. Once inside, they asked if I was ok and then left the bathroom without closing the door, so everyone got to listen as I, finally, after several hours of waiting to be able to stand, got rid of 10 hours worth of saline that had been collecting in my bladder. Feeling quite relieved, I then began to wash my hands.

One of the nurses came back in to check something and then left again, partially closing the door behind her and giving me a false sense of privacy. As I was carefully washing my hands while simultaneously trying to keep my back to the wall so as not to flash a re-entering nurse, I heard a man's voice in my room. Figuring it must have been my plastic surgeon, Dr. Smith, I quickly rinsed the rest of the soap from my hands and pulled two paper towels out of the dispenser. The door suddenly swooshed open and Dr. Smith approached me with almost startling speed. As he tore the snaps on the shoulders of my gown apart and pulled it down to expose my entire chest, I looked up at the bathroom door and was horrified to discover that five interns were there, watching. I tried very hard to pull my gown around, but the tubes and wires coming out of the left side – the side facing the interns – would not allow it. So there I stood, only my arms and stomach covered, the tubes and sink mirror revealing all else to the eyes crowding the bathroom. “Looks good,” he said casually and hurriedly snapped my buttons up and whipped out of the room saying “I’ll be back tomorrow,” as he left. Right then, in that moment, I wanted to disappear. *Poof* Nothing to it. Just disappear. If not physically, then mentally, please, remove that memory – I don’t want it.

When my good friend Becky came to visit and we were left alone in the room for a few moments, I asked her to close the door and help me put on the pajama pants in my overnight bag.

Later that night, sometime around 3am, I decided to go the full four hour span between doses of generic Percocet without asking for a shot of morphine to tide me over. Doctors have, in the past, routinely told me not to let the pain get away from me. Unfortunately, neither Dr. Smith nor any of his interns reminded me of this gem of

information, and I had forgotten how difficult it can be to catch up to the pain once it has gotten away. I was miserable, I felt stupid, and I wanted to rewind and buzz the nurse as soon as my chest started burning. But that was not possible, and while morphine might be a great pain reliever, by that point it merely worked to maintain the level of pain I was experiencing and keep it from getting any worse. What was I thinking?

Why couldn't I be like Gibson's character Molly, the biologically modified muscle in *Neuromancer* who once had software implanted that allowed her to suspend consciousness but physically react to the world in pre-programmed, mechanical ways that she would not be able to remember? The technology was used by prostitutes, allowing them to engage in sexual encounters without having any memory of them. They called those prostitutes "meat puppets." Molly was using this method of prostitution so that she could afford her modifications – one of which included cat like, retractable razor blades implanted under her finger nails – so that she could move into the more engaging, more respected profession of killer/body-guard/spy.

Unfortunately, however, as Gibson would have it, the software failed and Molly began remembering things. At first, just as dreams, nightmares; but then, vividly, gruesomely, she started to remember everything, until one time she re-gained full consciousness while she was with a customer and killed him with her razor claws.

Just like the rest of the book, and like other books, movies and academic literature, Gibson seems to be telling us that technology is part of us, and we it, but that even with these innovations, these cyber landscapes and biological upgrades, we cannot overcome ourselves, and part of ourselves, for better or for worse, are our bodies – without them, we are nothing more than memory, ROM constructs; we are dead.

The pain that accompanies the various physically transforming procedures we undergo might be looked at as a right of passage. I mean, it only makes sense that I should have to pay a toll to have the peace of mind that my breasts can no longer kill me and to be able to say that gravity is no longer my enemy; the payment for these gifts that the technogods have chosen for me – besides large sums of money – is months of pain, discomfort and physical inability. We cannot expect to make these transformations with the utmost ease and pleasure, and people who have written stories about it have very clearly addressed this, although the rough spots and danger for them seems generally to be centered in the social change and inhumanity involved rather than the physical aspect.

We are creatures of technology, giving ourselves the gift of life through various innovations and fearing what we may become because of it. We want to be unique, sometimes forgetting that our technology is part of what makes us different and instead fearing that it will make us all alike. But even silicone gel implants look different on different women, because our bodies – the other thing that makes us unique – incorporate technology differently. Escaping the consequences of our actions – whether they are physical, mental, social or a combination of all three – through means such as Molly's implanted software is what would make us all the same, make us all meat puppets.

All things considered, I suppose I am thankful that I remember all of the most horrid physical sensations I have so far experienced, and I suppose it would be important to give Dorian more memory of the pain and suffering that he surely experienced through all of his surgeries. After all, no pain, no gain, right?

Conclusions

The medical world is strange, sometimes frightening, often distressing and somehow seems larger than the “regular” world. At the time, it seemed like I was just doing it, just kind of existing in this world where being tested, stabbed and drugged was normal and where if it didn't hurt, you were doing it wrong. At the time, existing in that world with those expectations, it did not seem very strange at all, nor was it very frightening. I could say that I'm just very good at adjusting to foreign situations, at accepting that there are different forms of “normal” for different circumstances and naturalizing these various normalities to my sense of understanding. I could also say that I'm very good at disassociating myself from situations I find myself in – that I step back from the situation and act more like an observer than a participant. Both explanations are plausible, and both are partially true in their own right, but they are not complete explanations by any means.

Previously I discussed the internalization or naturalization of technology by humans. We treat our cellphones, our vehicles, our clothes and our internet devices as extensions of ourselves – they contribute to our modes of being, our understanding of ourselves and the way that others view us. We make ourselves accessible and access our surroundings through these devices. Fiction works similarly.

Prior to my cancer experience, I read a lot of fiction and imagined a lot of stories. *Neuromancer* is one of my favorite books and I have read it repeatedly, although I imagined Dorian Maximus even before I even knew about Case and Molly. Regardless, *Star Wars*, the *X-Men* comics and movies, *The Matrix*, *Bladerunner*, *The Terminator* series, the television shows *Star Trek* and *X-Files*, Franz Kafka's *Metamorphosis*, C.S.

Lewis' *Out of the Silent Planet* series, Mary Shelly's *Frankenstein*, Orson Scott Card's *Ender's Game* series and many other works of fiction were read, watched and internalized throughout my life. These works unquestionably influenced my modes of understanding the world and acting within it, and most certainly prompted my imagination to create Dorian Maxiums. When I discovered Jason Bourne and William Gibson's cast of characters in *Neuromancer*, I felt a sense of pride that I had created a character that was kind of a hybrid of their stories, but at the same time I felt let down that it was not a novel idea.

But I hadn't come up with Dorian by myself in the first place; I had many, many prior influences that made me think in very different ways, imagining very different modes of “normal.” Only then was I able to find Dorian.

Similarly, I did not accept the medical world as “normal” on my own – I did not simply fall into cancer and assimilate. Rather, I fell into cancer with Dorian, Wolverine and Rouge, *Neuromancer*, *The X-Files*, *Frankenstein*, *Bladerunner*, C.S. Lewis, Orson Scott Card and Franz Kafka. I fell into cancer by myself, but not alone.

In retrospect, I understand that my mental internalization of the lives and worlds of the characters that all these authors and film makers have created is what made the physical internalization of the medical world so much less strange and frightening. Fiction provided me with theory, which is quite simply a mode of understanding. I applied the theory, the modes of understanding, to my circumstances and my way of being in the world I found myself in. Theory allowed me to think about my situation in many ways, often manifesting itself as a story that I was part of. “*How would they write about this?*” I often wondered to myself, “*How would Gibson describe this?*”

In addition to academic theory, the theories we derive from fiction work as explanations and coping mechanisms for the weirder times in life. Using the various theories we pick up along the way to explain personal experiences, and then using those experiences to add to theory, we have yet another mode of understanding and yet another way to view the things we see, hear, read and experience.

Theory is not derived from nothing, nor is our being in the world.

Aftermath

There is not an end, and I hesitate to draw definitive conclusions. What I hope to have shown, among other things, is precisely the non-definitive nature of social being and theory (which are, in a sense, the same). We derive theory from existence in an attempt to rationalize the world as we know it – or at least as we desire to know it – and as we move through life perpetuating social norms and living in our theory, some of us stumble, push, resist, and something begins to change. The change starts out as an obvious resistance, a ploy to move, tear down or color standing social structures. After a while, it turns into the norm that we perpetuate, the mode we exist in, and, eventually, resist.

And so we continue in a cycle of acceptance and discontentment, restlessly shifting our understanding from one foot to the other, sometimes recklessly. Recognizing theory as a mode of understanding and explanation is useful and at times necessary to successfully navigate unfamiliar social territory, as well as to effectively resist entrenched social ideals. After all, we must know the rules before we can break them – at least if we want to make any sense.

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