

**Rehabilitation from Death?**  
**Part of a work in progress (*Am I Cyborg?*)**  
*Reflexive Meditations on Rehabilitation*

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The title of my paper ends with a question mark—“Rehabilitation from Death?” I mean by this two things: 1) to highlight my own uncertainty about the juxtaposition of the two concepts, and 2) to make my presentation more question and far less lecture. It is not a finished or stand-alone presentation. It is a part, perhaps the first part, of another larger project. The study, which I hope to present in the near future, looks into the role that biomedical and biomedically-sanctioned techniques of disability rehabilitation play in today’s complex and possibly posthuman (yet still all too human) lives. Its proposed title, “Am I Cyborg?” ends with a question mark as well, although this leads into a subtitle: “Reflexive meditations on rehabilitation.” The overall research project is thus intended as a phenomenological “meditation” and not an “argument”, “thesis”, or some other neat academic sort of endeavor. In this autoethnographic meditation, I will examine my own life and experience as a “rehabilitated”-yet still disabled survivor of a severe traumatic brain injury (TBI). However, “Am I Cyborg?” is not an autoethnography. It is meant to be a kind of public thinking through what happens when I turn my anthropologically trained gaze back on myself. It is a reflexive project, a querying and *not a claiming* of a life and subjectivity made possible by powerful new biomedical techniques and technologies.

The point of the present exercise is not to psychoanalyze myself, my story, or anything else; I rather want to make an otherwise esoteric theoretical position, a kind of subjectivity, real and (literally) placed in front of you. Through this public meditation, the first I have ever done with an audience of more than three or four other persons, I hope to problematize the idea of certain kinds of death and the certain kinds of

lives that have approached but returned from those kinds of death. The question that I hope to present and leave you with is thus central to this conference: what should we say about death, when, thanks to heroic biomedical techniques (and the technologies that support them), we can bring damaged bodies and brains back from the brink of death, from that which *would have been death* only a few years ago?

### **My Own Story of Rehabilitation**

I will not dwell too much on my personal narrative of what led me to write this paper. But I do need to give you the bare bones of my story in order to explain the curious and in many ways objectionable question it poses. I hope that will be enough for the purposes I set out in this paper:

In April 2003, I was in Egypt as my post-graduation Fulbright grant to Kuwait was put “on hold” for the U.S.-led War on Iraq. While crossing the street as a pedestrian in the southern city of Luxor on April 24, just south of Karnak temple and east of the Valley of the Kings, I was struck in the head by the mirror of a passing tourist bus. The bus speedily continued on by as if nothing had happened—or so I am told—and I was knocked bloody into the middle of street, already deep in a coma. I was ultimately diagnosed with a “very severe” TBI, though I waited in a comatose and semi-comatose state for several weeks for this diagnosis. My final diagnosis found that I suffered a “severe diffuse axonal TBI” that gave me a spontaneous Loss of Consciousness (LOC) for 6 days, a Glasgow Coma Scale (GCS) of 4, and Post-Traumatic Amnesia (PTA) lasting approximately 45 days. That means that I remember nothing from the morning of April 24 until my 23<sup>rd</sup> birthday, June 7<sup>th</sup>. When I woke that day, I remember being in immense pain, unable to move, disoriented, and frightened as my parents came singing “happy birthday” to me. This inexplicable scene happened in a strange-smelling room in a strange building with all these strange people in blue scrubs who kept telling me to stop pulling the tubes out of my arms.

All in all, I spent six days in a fully unconscious state

and two more weeks in a semi-conscious state in two hospitals in Egypt, a total of 3 months in hospitals in both Egypt and the U.S. (where I was medically evacuated on May 10, 2003), the next 1.5 years of my life in outpatient rehab learning to walk, talk, and clean myself. I have spent all of the ensuing 12.5 years in and out of varying programs of diverse rehabilitative therapies in several different locations in the U.S. and Africa. Throughout this time, much to my personal chagrin, my physiatrists<sup>1</sup> and various therapists would tell me that I needed to “let my old life go”, to “start a new life”, to “grieve for what I once was” and presumably could no longer be. They did not offer answers about who or what I *was*, or who I could *become*; they only seemed to say that “Austin” had ceased to be on that fateful day on the Nile and that “I” would need give up the idea of myself in order to move forward with my life. The two subjects of their discourse do not seem to be the same, and ever since first receiving this “advice” in the hospital, I have thoroughly resented it.

Today, owing to rehabilitative techniques and several other factors (the aid and support of family and friends, intersecting identity factors, and the growing awareness and acceptance of TBI as a dominant feature in survivors’ lives), not only can I walk, talk, and write again, I have even returned to my pre-injury academic career plans. Yet I am doing them differently than I had first planned: neither my research subject, what I call “the social life of TBI”, nor even my *way* of researching is the same. Every moment of every day, that subject forces itself on my consciousness and has to be dealt with in order to get along with whatever I happen to be doing. In effect, it *is* my consciousness. I do not mean to say by this—not really—that I am researching myself in my graduate studies. Rather, because TBI and TBI rehabilitation are indelibly a part of everything I do, intellectually and at a more foundational level (moving, seeing, breathing), I want to research and understand what makes it so. Like many other TBI survivors, I now have and will probably always have

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<sup>1</sup> No, this should not read “psychiatrist.” A physiatrist is a doctor specializing in physical rehabilitation.

abnormal balance problems, coordination issues, double vision, unpredictable memory, impulsivity, lack of emotional control... The list goes on and on, but I do not mean to.

I mention all of this primarily to show that I am in many ways *not* the same person that I was the morning of April 24, 2003. Anthropologists and sociologists who have studied the matter, like Laura Krefting (1992), Monica Casper and Daniel Morrison (2012), as well as my psychiatrists, neuropsychologists, and neurologists who have worked with hundreds of survivors every year concur: there is a fundamental difference at some of the deepest and most profound levels before and after a TBI.

## TBI

Traumatic Brain Injury, in its clinical formulation, is relatively simple to define. The U.S. Centers for Disease Control and Prevention (CDC) refers to it as “An occurrence of injury to the head that is documented in a medical record with one of the following conditions attributed to head injury: (1) observed or self-reported decreased level of consciousness, (2) amnesia, (3) skull fracture, or (4) objective neurological or neuropsychological abnormality or diagnosed intracranial lesion (CDC 2010).” Essentially, TBI happens when the brain is hit by an object external to the brain itself. This can be accomplished by a fall, a physical blow to the head, force from a blast, explosion, or even penetration of the brain by some external object, such as a bullet. Often the primary injury is compounded by the brain rebounding inside of the skull, thus damaging the brain at several different locations (my injury was focused in the left frontal and right temporal lobes). The ways individual brains are impacted can be more complex than this, but the typical injury remains remarkably singular.

If the definition of TBI is relatively clear-cut, its quality or classification of severity can be more problematic. As one recent rehabilitation handbook put it, “compromise or injury to the brain is typically defined as a manifestation of some alteration in consciousness which ranges from feeling

dazed and confused to loss of consciousness/responsiveness, as in coma (Roebuck-Spencer and Cernich, 2014:4)"—quite a large spectrum. The vast majority of biomedical clinicians and pathologists use a simple tripartite scale (mild, moderate, severe), to diagnose this range of severity, but they define each of the three levels differently. Some prefer to judge a patient depending on LOC, while others focus on PTA. The final and most widely used scale is the GCS, a 3-15 point scale that combines three different measurements of the injured body's response to stimuli. A post-injury GCS of 13-15 is considered mild, 9-12 moderate, and less than 9 is severe. The vast majority of TBIs are mild, often referred to as "concussions", and do not require immediate hospitalizations. Yet still many others are moderate-to-severe, frequently resulting in biological death. Those that survive these injuries suffer the loss of consciousness and memory, and nearly all have some amount of irreversible brain damage.

TBI's impact on survivors' lives, on their families and wider communities is even more complicated. The brain is implicated in almost all human activities (both conscious and unconscious), and thus an insult to the brain can be considered an insult to all of those activities. Rehabilitation medicine and treatment is concordantly also diverse, comprising psychiatry, physiotherapy, speech pathology, occupational therapy, psychotherapy, and even recreational therapy, social work, and a great many more. Each of these practices constitutes a separate discipline. Tracing out their unique ways of knowing, strategies for constituting and affecting their subjects, and the techniques which they inscribe into the bodies and lives of TBI survivors is the subject for my larger cyborg project.

What I want to highlight in my current presentation is that the complexities of my own case are in no way unique. According to the CDC in 2010 alone, there were 2.5 million emergency department visits, hospitalizations, or deaths associated with TBI. Even though most of these cases result in full recoveries either spontaneously or with the help of biomedical and rehabilitative techniques, what can rightly be called "recovery", a significant minority of TBIs—including

my own—do not. As clinician turned medical anthropologist David Aldridge bluntly put it, “As a result of traumatic brain injury, people change...(and sometimes) it is inappropriate to consider (treatment) in simple terms of reversibility (2008:18).” In other words, for millions of Americans *every year*—and thus for millions of individuals around the globe—these injuries thrust change (and not just any change, but change in their *experiences of the world*) upon them.

For those of us who survive more severe and often-fatal head injuries, it is as if our former lives *end* and our new lives *begin*. In the film by the late James Gandolfini, *Alive Day Memories: Home from Iraq* (2007), at least one of the returned soldiers who had also survived a severe TBI (and other injuries) mentioned that he had actually “expired” three times on a helicopter as he was med-evaced from war zone to medical center. Several more said that their former lives were over and that they would need to habituate themselves to new ones. Granted, these soldiers’ experiences may seem extreme and the idea of “Rehabilitation from Death?” may appear an untenable position to take. But I am speaking of my own much more ordinary experience, not theirs. I no longer “feel” the same, both physically and psychically, and every moment of every day is testament to the fact that my embodied existence is *not* what it was before that fateful morning on the Nile. The left side of my body in several places does not feel or feel fully, seeming permanently “asleep” or numb. Several places in my memory, even of one family member passing away, are dark and simply not there any more. There are new bodily curiosities about me, as well—ataxia, double vision, the fact that my collar bone sticks juts out of my shoulder instead of attaching to it. They are all perfectly human and (possibly) even “normal” conditions, or at least “normal” for some. But there is one important element to them: they were never a part of my lived experience up until my 23<sup>rd</sup> birthday. Now, I cannot escape from them, even when thanks to rehabilitation I can hide them from the world. In many ways, it really *is* as if “I” passed away in 2003, even as “I” am still here today. Thus I must ask the question: can my TBI rehab be akin to rehab from

death? Ultimately such a question demands less an answer and more of a rethinking, not so much of what death is as of what life—especially a life rehabilitated from the brink of death—can be.

### **Three Implications for the Study of TBI**

If the analysis of TBI rehabilitation can lead to such radical and yet fundamental questions, why has social science not yet taken it up—at least, not in any systematic way? In this section of my presentation, I want to step away from myself (if that is even possible) and briefly dwell on three potentially fruitful questions for social scientific, most significantly medical and sociocultural anthropological, studies.

The first is why TBI, a fundamental reality of contemporary human and posthuman existence, has evaded social science until recently. Some may argue (and have argued with me) that TBI is relatively new diagnosis, and so of course anthropologists have not thoroughly dealt with it; this is to some extent true. TBI has existed as a recognized subject of the biomedical intervention for most of the last half-century, but I do not think it was a topic of regular public interest before the 2<sup>nd</sup> Iraq and Afghanistan wars. Alan Young, in his masterful and influential study of PTSD among vets of the Vietnam War, only mentions head injuries a few times (1995). Indeed PTSD is often comorbid with TBI, though it has a separate clinical diagnosis and describes an entirely different condition (Bryant, 2011). That the two are so easily conflated in public discourse today implies that TBI has never before been popularly understood as a distinct diagnostic category. Moreover, disability in general, even in a visible form like paraplegia, has only recently entered the canon of academic subjects (Rapp and Ginsburg, 2013). Perhaps for these reasons, as well as that brain injuries do not have a standardized set of symptoms, TBI has never received sustained attention from social scientists. If they do take it up, as a great many are starting to, what then? What new understandings and discourses surrounding TBI, such as its relationship to death,

might arise? Simply, what are the circumstances in the recent past and present that have allowed TBI, considered a timeless biomedical diagnosis, to emerge as an object of study?

Second, as I suggested above, TBI creates a very new kind of subject. This is one characterized by a fundamental phenomenological break with the past. Gilbertson and Aldridge (2008) rightly points out that the body, including the brain and its functions, does not emerge unaltered from severe accidents or assaults. A GCS of three or four implies significant and—and this is important—permanent brain damage. The self that emerges from coma does not have the same feelings or even the same *capabilities* of feeling as before. Yet through rehabilitation, indeed through all of life after coma, the injured brain “recovers” or “comes back” to full(er) function. I do not mean this in the sense that the severely damaged brain somehow returns to its prior state, but in the sense that it learns *anew* and *again* but *differently* how to behave in certain situations. What is this “coming back”, if the brains of the “recovered” are, in essence, newly formed and distinct from the ones that were injured?

And finally, my meditation on death is implicated in the uncomfortable debate surrounding organ donation. Lock and Nguyen’s influential essay on the subject, “The Social Life of Organs,” a chapter in their monumental *Anthropology of Biomedicine* (2010), is clearly related here. They claim that, “Creation of the concept of ‘irreversible coma’ in 1969, later modified to ‘whole brain death’ in 1981...permitted the procurement of organs for transplant from patients in this condition on the grounds that they are dead (238).” In other words, individuals in a state of “irreversible coma”, whose bodies can continue to live only with sustained biomedical intervention, can be effectively and legally (in the United States and many but not all other countries) killed to further the lives and utilitarian ends of other people. I believe that this argument is in most cases justifiable, as I have been a registered potential “organ donor” both before and since my injury. But it is far from a clear-cut and ethically pristine argument. Rather, it needs to carefully taken up and thought over by social scien-



tists, biomedical ethicists, and health policy makers, among others. For the question needs to be answered (by someone): how can society proceed with organ donation when there are now a (very) few cases in which an at one time “irreversible coma” has become “reversible”, thanks to newly-developed heroic and very resource-intensive medical actions?

### **Concluding Remarks on Intentionality**

What is my purpose in presenting this work in progress, in presenting this imperfect and unfinished presentation? In disclosing and discussing my own story, I do not mean to *do* anthropology, although this rough essay is certainly informed by the academic methods of anthropology. It is not to academically anesthetize and present my own story as an autoethnographic case study of some larger social reality, either (although that would be worthwhile). Rather, it is threefold: To present evidence from lived experience that problematizes a simplistic common-sense boundary between death and life; To indicate the need and some potential avenues for further discourse, thought, and research on the subject; To serve a personal need to air and come to terms with my own lived reality.

In that last regard, this is (actually) the very first time that I have presented my own story in any sort of professional fashion. I do not feel that it takes away from the presentation that one of my purposes is self-serving, however. It has been important for many if not all who use autoethnographic methods. Truly, is that not part of the reason why *all* anthropologists conduct their work, from the foundational scholars of our discipline like Boas, Benedict, and Mead to today’s anthropologists like Rapp and Ginsburg (both parents of children with significant cognitive impairments)? I hope, in presenting my own deeply personal story to have followed in their footsteps—if only in presenting a “work in progress.”

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