Lost in Techno-translation: Diagnosing and Treating Cyborg Patients in Biomedical Practice
by
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Preface

I was diagnosed with Crohn’s Disease towards the beginning of my freshman year of high school. My symptoms began on October 8, 2010, my 14th birthday. After a night of eating and celebrating, I spent the following morning lying in fetal position on my bedroom floor, grasping my stomach in agony. Everyone gets gastrointestinal (GI) symptoms once in a while, so I quickly dismissed this as a fleeting stomach upset and carried on with my day as best as I could. Intermittent pain visited me every day in the following week, but I continued to shrug it off. One day, however, my pain manifested in an intensified form. It felt as though someone took a chainsaw and sawed through the inner lining of my stomach. I went to the bathroom for relief and saw a bright red liquid infiltrate the toilet—a literal “red” flag marking my disrupted internal state. My body was screaming for attention and I could not ignore it any longer.

I told my mom about my recent symptoms and she responded immediately, but at this point my body was deteriorating at a rate too rapid to address. Every day, the chain-sawing would hit me with increasing intensity and frequency but most importantly, without warning. In the middle of a math test or tennis match, a tsunami of pain would consume my body such that at best it left me paralyzed, and at worse, left me sprinting to the bathroom. As my symptoms progressed, I became exceedingly unable to participate in the activities that gave me such a strong sense of purpose and happiness. Just as debilitating as these physical symptoms, however, was the immense sense of isolation and embarrassment I felt when struggling to maintain a sense of normalcy and independence amidst the internal battle that had launched
inside of me. As a teenage girl, the isolation I felt was largely perpetuated by the ongoing requirement to meet a certain standard of “perfection” with respect to both actions and looks. Running to the bathroom every 15 minutes and embodying the appearance of a 90-pound skeleton, hardly made the cut.

During this time, my mom took me to more than five different specialists including my general pediatrician, an immunologist, orthopedist, acupuncturist and gastroenterologist. While they technically had different focuses and academic backgrounds, to me they were all the same—middle aged men with salt and pepper hair wearing suits confined by a white coat that reeked of hand sanitizer and a superiority complex. They would all greet me with the same “Splenda-sweet” smile that they probably mastered late one night in medical school in preparation for a clinical exam. While they may have fooled their med school instructors with this saccharine bedside manner, they could not fool me. In our interactions, it seemed that they saw me as but a set of numbers and symptoms in need of drugs and procedures. I couldn’t care less what my weight or blood counts were; I just cared about being able to play in my tennis match the following day and attend the party that upcoming weekend. Everything else was just white noise. Of all the physicians I saw, the gastroenterologist’s illiteracy in reading teenage girls was especially noteworthy. After making initial introductions, the doctor eyed me up and down, visibly taking note of my physical aberrations before summarizing them to his shadowing resident. “In the past few months, Julia has lost 25 pounds, been having several loose bloody bowel movements a day, and labs show systemic inflammation and severe anemia—hence her small and pale demeanor. Symptoms point to Crohn’s disease.” Honestly, it
was pretty impressive; in just one succinct sentence he was able to draw attention to my biggest physical insecurities all at the same time! He proceeded to ask me a host of perfunctory clinical questions before demanding that I get a colonoscopy “ASAP.” Now maybe I was a little dramatic, but I’d say that for most 14-year-old girls, the idea of anyone, let alone a middle aged stranger sticking a scope up your butt, is not a very compelling thought to engage in. I refused.

Eventually, I found a doctor who recognized my clinical symptoms as synergistically existing within the broader system of my being. This doctor, who I have been a patient of for almost eight years now, recognized that in order to effectively address my disease process, she first had to address the social environment of “teenage girl culture” in which the disease was intertwined. Throughout the years, I’ve heard my doctor seamlessly make reference to Beyonce lyrics and reality TV shows in between describing the pathogenesis of Inflammatory Bowel Disease and the metabolic mechanism of complex pharmaceutical drugs. Her sensitivity and interest in my broader social and cultural environments have been crucial to instilling a foundation of trust that has made me feel comfortable communicating my needs, concerns and priorities to her, as well as listening to her proposed assessment and treatment plans.

My experience with getting diagnosed was my first exposure to the power imbalance embedded in the doctor-patient relationship. Of course, as a 14-year-old, I did not have the Science in Society background that I have now such that I could make sense of my experiences with these clinicians through the lens of established sociocultural and political frameworks. However, I did not need to be acquainted with
Foucault and Latour in order to feel that the first doctors were promoting clinical and technical health markers at the expense of minimizing my subjective experience.

Fueled by my negative experience with the first doctors and inspired by the humanistic and scientific brilliance of the second one, I entered college as a hard-core premed. I took a host of biology, chemistry, and immunology courses where I gained a tremendous amount of knowledge about the molecular basis of disease. Additionally, for two summers I worked as a clinical research coordinator at a prominent IBD tertiary treatment center in New York, where I conducted clinical research using electronic technological communication systems, attended weekly case conferences, journal clubs and pathology sessions, as well as shadowed clinicians at the center during their patient consultation sessions. Through these experiences, I developed a tremendous amount of tacit knowledge regarding the process by which clinicians understand patient disease embodiment and make treatment decisions through technological tools. In attending patient sessions, I also gained firsthand insight into how patients interpret objective biotechnical information regarding their disease diagnosis, treatment options, and objective disease and drug markers.

In this thesis, I investigate how the influx of biotechnologies into clinical practice has perpetuated the power imbalance—what I refer to as a “chasm”—between doctors and patients (specifically with Crohn’s disease). I have been on and sympathize deeply with both sides of this chasm and have frequently struggled to reconcile both perspectives. The Science in Society Program (SISP) at Wesleyan has provided me with critical frameworks that have given me insight into my own disease embodiment and subjective experience as a patient. SISP has additionally instilled in
me a sensitivity and awareness of how sociocultural, political, and medical institutions shape broader conceptualizations of health, happiness and personhood. In writing this thesis, I set out to reconcile competing perspectives between clinicians and patients, as well as within myself.
Introduction

The medical model for disease management originally dictated that treatment decision making should fall exclusively under the jurisdiction of the clinician, who was seen as the sole proprietor of bodily knowledge. In the early 1980s, however, a new model for collaborative treatment decision-making emerged in practice that promoted patients and caregivers as focal members of the decision team. This model, called Shared Decision Making (SDM), is characterized as “a key component of patient centered healthcare. It is a process in which clinicians and patients work together to make decisions and select tests, treatments and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values.”¹ According to Charles et al, there are four core characteristics of shared decision making: (1) that at least two participants—physician and patient be involved; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement.²

The SDM model first gained traction as part of an effort in the medical community towards emphasizing patient autonomy, improving physician-patient communication and informed consent in the health care system.³ Shared Decision Making recognizes that every patient has a unique physiology, social background,

² Charles, Cathy, Amiram Gafni, and Tim Whelan. "Shared decision-making in the medical encounter: what does it mean?(or it takes at least two to tango)." Social science & medicine 44, no. 5 (1997): 681-692.
and unique belief system about disease causation and treatment that may differ from their physician. They also have differing ideological and practical models for conceptualizing and addressing risk states and disease diagnoses. The goal of SDM is to develop a model that addresses the needs, values, and concerns of both the patient and the physician.

Table 1 outlines some patient outcomes from and physician feedback about SDM practices as presented by the Shared Decision Making fact sheet.

**Table 1: Outline of patient outcomes from and provider attitudes towards SDM.**

<table>
<thead>
<tr>
<th>When <em>Patients</em> engage in shared decision making they…</th>
<th>What <em>Providers</em> say about the value of SDM$^4$</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Learn about their health and understand their health conditions</td>
<td>• Patients are more knowledgeable and better prepared for dialogue</td>
</tr>
<tr>
<td>• Recognize that a decision needs to be made and are informed about the options</td>
<td>• Helps the patient understand what we are trying to do</td>
</tr>
<tr>
<td>• Understand the pros and cons of different options</td>
<td>• Builds a lasting and trusting relationship</td>
</tr>
<tr>
<td>• Have the information tools needed to evaluate their options</td>
<td>• Both physicians and patients are satisfied</td>
</tr>
<tr>
<td>• Are better prepared to talk with their health care provider</td>
<td></td>
</tr>
<tr>
<td>• Collaborate with their health care team to make a decision right for them</td>
<td></td>
</tr>
<tr>
<td>• Are more likely to follow through on their decision</td>
<td></td>
</tr>
</tbody>
</table>

In theory, the SDM model aims to minimize the power gradient between doctor and patient through minimizing the medical knowledge gap between each.

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party. However, the content and organization of this table indicates that the power discrepancy embedded within the doctor-patient relationship has not necessarily diminished through SDM practices; rather, it has merely been transformed. This idea is demonstrated by the table’s binary organizational structure that was presumably designed to present doctors’ and patients’ perspectives as being equally valued by the SDM model. Under this assumption, it is evocative that the headline for the ‘doctor’s perspective’ column showcases the active voices/opinions of physicians (“What providers say about the value of SDM”), whereas the patient’s column merely presents patient effects through a passive, third-party voice (“When Patients engage in Shared decision making they…”). The content of each column further illustrates the doctor-patient power discrepancy embedded within SDM practices. For instance, that physicians boast SDM for the way it “helps the patient understand what (they) are trying to do” implies that the ultimate goal of SDM isn’t necessarily to provide a “middle ground” between disparate doctor/patient value systems; rather, it is to teach patients to think and conform to the ideologies of the dominant biomedical knowledge structure. When clinicians claim that “patients are better prepared to talk with their health care provider” after participating in SDM (as listed in Table 1), they are arguably referring to the efficacy of SDM in teaching patients how to think about their health and body, and communicate using the language and bodily representation models dictated by the biomedical system.
Several studies have investigated how clinicians’ exertion and perception of power have changed amidst the newfound patient-centered rhetoric of SDM.\textsuperscript{6} While most clinicians support the notion of a more equalized relationship with patients, many are aware of an inherent power imbalance that exists by virtue of them possessing expert knowledge.\textsuperscript{7} According to Foucault, this knowledge is an embodiment of power embedded within social institutions. Power is not inherently positive or negative but exists in all social relationships, including that between doctor and patient. Power “comes into being” when it is exerted through “strategies.”\textsuperscript{8} Within the medical institution, language is a primary strategy in which physicians exert their institutionalized knowledge and power.\textsuperscript{9}

The language clinicians use to describe a patient’s physical body, health, and pain, has massive implications for how patients subjectively experience disease and suffering.\textsuperscript{10} In order to understand how a clinician’s knowledge/power informs and/or conflicts with the patient’s interpretation and embodiment of illness, it is first crucial to understand the representational systems used to signify their meaning. The goals of the SDM model, the transformation of the doctor patient relationship, and the rise of

\begin{itemize}
  \item \textsuperscript{7} Nimmon 2016
  \item \textsuperscript{8} Foucault, Michel. "The subject and power." \textit{Critical inquiry} 8, no. 4 (1982): 777-795.
  \item \textsuperscript{9} Bourdieu, Pierre. \textit{Language and symbolic power}. Harvard University Press, 1991.
  \item \textsuperscript{10} Buchbinder, Mara. \textit{All in your head: Making sense of pediatric pain}. Univ of California Press, 2015.
\end{itemize}
current biomedical representation systems were all facilitated by the influx of technoscientific innovations into medical practice during the early 1980s. Technologies such as computerized health data systems, genomic technologies, external medical devices, interactive decision aids, personal health records, secure electronic messaging, and heterogeneous online disease information portals drastically transformed treatment decision and communication practices through creating and imposing new systems for representing the body.  

These biotechnologies drove the production and use of new forms of scientific and clinical knowledge—a new language—so to speak, that values numeric biomarkers as the gold standard for capturing “objective” narratives of pathology, health and risk. These endpoints transformed the way the physical body was defined and surveilled, and how disease was conceptualized and treated both in the removed laboratory setting as well as in the intimate clinical encounter between physician and patient. Specifically in the context of SDM, computerized decision-making tools use objective measures from genomic, histologic, serologic exams, and imaging assessments, in tandem with information regarding a patient’s demographic background and medical history, as the basis for making treatment recommendations.  

Given clinicians and decision-making biotechnologies were produced from the same biomedical value system, they hold similar assumptions regarding the

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discrete, material ontology of the human body and disease. This assumption is what allows them to view objective bio-endpoints as accurate, comprehensive representations of a patient’s disease and suffering bodily truth. Meanwhile, many aspects of the patient’s disease embodiment and belief system are negated as irrelevant to their care. What consequences ensue when the patient’s lived experiences and symptomatology cannot properly be signified by the output of the technology?

In this thesis, I argue that as clinical care, disease conceptualization, treatment monitoring and preventive practices have become increasingly guided by distant computerized data, a chasm has formed between clinical objective markers and subjective embodied experiences—between doctors’ priorities and patients’ stories. This chasm is a manifestation of the doctor-patient power imbalance embedded within the SDM model. It manifests with respect to the differing explanatory models of symptoms between professional and layperson (i.e. for questions like “why does my stomach hurt?”)—but also can be seen with respect to varying beliefs about patient empowerment, agency, disease management, and conceptions of quality of life.

Despite the biomedical system’s assumption that the patient’s personal and cultural background is not relevant to the interpretation and application of technological data, the reality is that drug therapies, diagnostic technologies, drug surveillance tools, and communication technologies inform and are informed by two separate, albeit dialectical relationships: 1) these biotechnologies act (and are acted upon) by the patient’s lived experience, priorities and belief systems; and 2) they act
(and are acted upon) by the physician’s end goals, etiology models, and interpretation of their quantitative, ‘objective’ metric systems. In many ways, these competing dynamics are analogous to a tug of war match between clinicians and patients, with their respective beliefs and priorities pulling the objective biotechnological endpoints—the rope, so to speak—in disparate directions. In chapter two, I illuminate the clinical and technical mechanisms through which biotechnologies exacerbate the chasm and pull the rope back and forth between clinicians and patients. Specifically, I take on the case of Inflammatory Bowel Disease (IBD), in which I focus my analysis on two biotechnologies that have recently entered the field. The first is a biologic drug therapy called infliximab, whose clinical and molecular properties have produced objective endpoints that have become the gold standard for monitoring and surveilling disease activity. The second biotechnology I examine is a drug surveillance assay that monitors a patient’s blood serologic drug levels, and which is used to guide decisions about drug use and dosing through a paradigm called Therapeutic Drug Monitoring (TDM). In tandem with its associated drug, TDM surveillance technologies produce quantitative data points that have influenced communication and decision making practices between doctor and patient.

To make sense of this case study, I draw upon the theoretical frameworks of cyborg theory and biomedicalization. In the past decade, science and technology scholars have used the concept of the ‘cyborg’ as a means to interpret new modes of subjectivity, ontology, and relationality that have emerged from the entanglements between humans and machines. With the understanding that communication problems
are inherently representation problems, the cyborg provides a theoretical basis for understanding how objective endpoints produced by technological bodily representations fail to capture the totality of the entanglement between humans, drugs, and surveillance technologies. How has the creation of human-machine hybrids perpetuated communication barriers both within a body and between patients, physicians, technological representation systems and bodily truth? How have shared-decision making practices, health outcomes, and patient engagement shifted or failed to shift in response to the creation and needs of cyborg patients? The framework of biomedicalization provides additional support for making sense of these questions, as it elaborates on how technoscientific infrastructures and human action/identity co-produce one another within the biomedical institution. I will elaborate in greater depth on the frameworks of the cyborg and biomedicalization in chapter 1.

Technoscientific innovations have pervaded the biomedical world at a rate so prolific that the protocols and social dynamics embedded in clinical care are lagging to keep up with the social and clinical demands imposed by them. Throughout this project I ask: what has been lost in translation between clinicians and patients as they negotiate new technological models for shared communication about disease and treatment? In short, the answer is the totality of the patient’s subjective experiences of health and happiness.

Chapter 1: Cyborg Theory and Biomedicalization

Since the cyborg’s first conceptualization in 1960, many scholars in the biological and social sciences have adapted the ‘cyborg’ term as a way to make sense of new material and social consequences that result from human-machine fusions. Thus, the framework of cyborg actually refers to a series of cyborg theories that were developed for different applications of analysis. In this chapter, I summarize several dominant cyborg theories and review how the cyborg has been analytically used by scholars in the field of science and technology studies (STS). Then, I describe key principles of biomedicalization that guide my understanding and analysis of the myriad clinical, social and technical relationships that have been transformed during this technoscientific age.

Cyborg Theory

Clyne’s and Kline’s first cyborg

In 1960, two NASA engineering researchers, Manfred Clynes and Nathan Kline, first proposed the “cyborg” in their article “Cyborgs and Space,” which discussed theoretical and technical strategies for facilitating human adaptation to the physical and psychological stresses of space travel. Their argument for “the cybernetic organism,” as they called it, was grounded in the logic that “altering man’s bodily functions to meet the requirements of extraterrestrial environments would be more logical than providing an earthly environment for him in space.”15 The cyborg

would meet the demands of these new environments by “deliberately incorporating exogenous components extending the self-regulatory control function of the organism.”¹⁶ These exogenous components would be comprised of various electrochemical, physiological, and electronic modifications that would regulate psychophysiological processes including cardiovascular control, vestibular functioning, oxygenization and carbon dioxide removal, fluid intake and output, enzyme systems, metabolic processes and hypothermic regulation, and muscular movement—all without requiring human consciousness or intervention for system operation. The integration of these parts with human flesh and molecular pathways, and the completely autonomous nature of the hybrid system, defined the cyborg’s ontology at this time.

Clynes and Kline described pharmacology as the dominant means by which to simulate biological and psychological equilibrium between an astronaut and their new environment, through a control loop of constant informational feedback.¹⁷ In the case that the astronaut should experience physiological or psychological distress while in space, Clynes and Kline discussed the possibility of pharmaceutical drugs being infused into the astronaut via remote control from regulatory systems on Planet Earth. The administration of drugs would result from decisions dictated by computer algorithms which model the organization of the body’s nervous system as a language of informatics.¹⁸ While Clynes and Kline described cybernetic pharmacological

techniques in the context of space travel, they explicitly noted that the notion of an automated pharmaceutical control system could be applied in medical treatment practices on Earth. In their remarks at the air force symposium in 1961, they stated that “what was discussed here is not only space oriented. It has implications throughout the field of mental health...The possible use of devices to...automate man...offers interesting opportunities for research that will benefit not only space travel but general medicine as well.”

Low and behold, the pharmaceutical vision that Clynes and Kline conceived as merely a sci-fi fantasy, has indeed become a medical and social reality.

According to sociologist Deborah Lupton, Clyne’s and Kline’s vision of a machine-hybrid fusion controlled by informatic feedback mechanisms has been configured in modern biomedical practices via new digital health technologies.

These digital devices may include devices that are worn outside of the body, such as smartwatches and wristbands (i.e. fit bits), as well as devices or sensors that are inserted into the body. These devices track bodily functions such as breathing, body temperature, lung function, blood chemistry, blood glucose, physical activity levels, and mood. Consequently, the digital technologies translate these physiological activities into technological data that can be algorithmically interpreted by computer systems and utilized by clinicians in order to make treatment or lifestyle decisions.

Modern day medical cyborgs reflect Clynes and Kline’s vision for the way that

19 Orr 2010, “Biopsychiatry and the informatics of diagnosis,” 359
assessments of patient health are measured by quantitative readouts, reflecting “objective” functioning. In emulating a system of autoregulation, the patient’s subjective experience is minimized as no longer central to evaluation and decision making.

Classifying medical cyborgs

The medical cyborg species is characterized by notable diversity with respect to the variety of intended functions that cyborg technologies may execute within a body and in society. Twenty years ago, Chris Gray conceptualized four types of cyborgs: restorative (restoring lost functions or limbs), normalizing (re-establishing normal functioning), reconfiguring (constructing new combinations of humans and technologies), and enhancing (extending human capabilities).21 Issues of relationality, subjectivity and embodiment must be interpreted differently in each of these four cyborg types, as each one carries nuanced discursive meanings. For instance, Craig Klugman contends that “while replacement stories often deal with issues of medical practice, enhancement stories deal with the relationship between physicians and society.”22 Within the neoliberal context in which biomedical cyborgs are situated, distinguishing replacement from enhancement technologies can often be difficult due to neoliberalism’s tendency to define “normalcy” as a function of what

22 Klugman, Craig M. "From cyborg fiction to medical reality." Literature and medicine 20, no. 1 (2001), p. 49
attributes (i.e. physical and psychological fitness) will best enhance the social and economic well being of the nation-state.\textsuperscript{23}

Klugman’s cyborg taxonomical system includes Gray’s replacement/enhancement binary but as part of a multidimensional model. That is, Klugman’s cyborg classifications are based on an axis system merged from the intersection of two binaries: replacement/enhancement and Cartesian/non-Cartesian. Cartesian dualism, coined after the seventeenth century philosopher, René Descartes, is a philosophical model that posits that the body and mind are separate entities that relate to each other in a dualism. Conversely, non-Cartesian models understand the mind and the body as existing in a cohesive, fluid system such that the two parts cannot be distinguished from or interpreted independently from each other. Both the replacement/enhancement and Cartesian/non-Cartesian axes are continuous spectrums, but together, they produce four concrete ideal cyborg forms (Table 1).\textsuperscript{24}

\textbf{Table 1}. The four ideal cyborg forms as described by Klugman.

<table>
<thead>
<tr>
<th>Replacement Body</th>
<th>Non-Cartesian</th>
<th>Cartesian</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Transplantable Body</td>
<td>Disembodied Mind</td>
</tr>
<tr>
<td>Enhancement Body</td>
<td>Super Body</td>
<td>Linked Body</td>
</tr>
</tbody>
</table>

In the following section I will briefly discuss each cyborg body according to their placement on the replacement/enhancement axis.

Klugman defines replacement bodies as human-machine hybrids in which one


\textsuperscript{24} Klugman 2001, p. 45
or more parts of the organic human have been replaced with mechanical counterparts to return function lost due to accident, disease or congenital anomaly.\textsuperscript{25} There are two types of replacement bodies: transplantable body (Non-Cartesian) and disembodied mind (Cartesian). In the former, mechanized parts are grafted onto the organic parts in order to replace one or more body parts and restore former physiological function. The transplantable cyborg body is one of the most common cyborg forms in biomedicine and is exemplified by humans who use cochlear implants, eye telescopes and dental implants.\textsuperscript{26} Transplantable bodies have been praised for the way that they improve patient quality of life as measured by biomedical metric systems. Klugman contends, however, that “quality of life is a value judgement about the experience of living. A subjective notion, quality of life is often a source of disagreement between patients and physicians.”\textsuperscript{27} Disagreement may result from disparate views on how to measure quality of life and/or how to define the parameters for what is considered an acceptable quality of life.\textsuperscript{28} This discrepancy may perpetuate the power imbalance and chasm embedded in the clinician-patient relationship.

The latter type of replacement body, what Klugman calls the disembodied mind, epitomizes Cartesian dualism by virtue of treating the cyborg body as an independent entity that is detached from the human mind. The disembodied cyborg has yet to become a medical reality. Consequently, Klugman’s analysis focuses on

\textsuperscript{25} Klugman 2001, p. 45
\textsuperscript{26} Klugman 2001, p. 46
\textsuperscript{27} Klugman 2001, p. 46
disembodied bodies as portrayed in science fiction stories. Klugman notes that “in disembodied mind tales, the patient/subject might be viewed as simply a body and the mind given less attention.”29 While not represented in current clinical practice, the disembodied mind illuminates several analytical questions pertaining to how cyber technologies may be perpetuating a treatment model that inadvertently separates the increasingly quantifiable disabled body from the qualitative identities and affective states of the body’s respective mind.

Enhancement bodies are human-machine hybrids in which exogenous machine parts and circuitry aim to confer functionality that transcends normal human ability. There are two enhancement bodies derived from Klugman’s dual axis cyborg model. The first type, the (enhancement) non-Cartesian “superbody,” is similar to Clynes and Kline’s original NASA cyborg in that its primary objective is to extend normal human physiological abilities so that humans can autonomously adapt to new environments. Modern day examples of superbodies include performance-enhancing steroids and cosmetic plastic surgery.30 Superbodies serve as useful analytical sites for examining how the pervasion of machines and digital spaces into biomedical practice has transformed disease conceptualization and treatment practices. Specifically, superbodies raise questions about how to best disclose information, diagnose and treat new disorders, identify the target of treatment, define parameters of normalcy, and cut away healthy tissue to install implants.31 All these components of biomedical practice are highly interconnected and work through the enhancement

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29 Klugman 2001, p. 48
30 Klugman 2001, p. 49
31 Klugman 2001, p.49
body in order to help an individual adapt to the demands of their physical and sociopolitical environments—what Klugman refers to as “the pursuit of a social ideal.”

The second type of enhancement body, “The Linked Body” (Cartesian) is characterized as a body in which “the human remains unaltered except for the implantation of a machine that enables him or her to connect to other individuals or computers.” Like the disembodied mind, the linked body has scarcely been implemented in current western medical practice. However, Klugman argues that the linked body represents the future of medical technologies and treatment practices, and specifically poses major implications for how definitions of “normalcy,” “pathology” and “risk” will be redefined in this new technoscientific age. The belief in the non-Cartesian “mind-body connection” can be traced as far back as the second-century.

However, as clinical decisions and risk stratification procedures have become exceedingly based on quantitative biometric data and technical algorithms, clinicians have increasingly promoted a healing system grounded in Cartesian dualism. This model—in which practitioners follow the numbers (of the body), at the expense of ignoring the lived experiences and narratives (of the cyborg mind) is already evident in an emerging paradigm of thought called personalized medicine. Later in this section, I describe the personalized medicine paradigm in greater depth.

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32 Klugman 2001, p.49
33 Klugman 2001, p.49
From Haraway’s cyborg to contemporary medical cyborgs

Towards the late twentieth century, Science and Technology Studies (STS) scholars started investigating questions of cybernetic embodiment through the ideas of Donna Haraway. In 1985, Haraway imposed new meanings onto the term ‘cyborg’ in *A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century*. In her work, Haraway proposes how the cyborg can be used to understand the transformative role, influence, and limitations of medical technologies for conceptualizing health, medicine, disease, and the body/human identity in this medical technoscientific age. Haraway’s cyborg theory especially became distinguished for her depiction of the cyborg as a metaphor for sociopolitical contestation and revolution.

Haraway defines the cyborg as “a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction…In short, we are cyborgs. The cyborg is our ontology; it gives us our politics.”36 Haraway’s “human-machine hybrid” refers to a body composed of both human and exogenous technological components. It is a fully integrated, homogenous composition of flesh and wires, a no-longer separable mixture of organic and inorganic parts. Haraway uses the breakdown of the human-machine divide as a metaphor for questioning the fixed nature of human ontology and embodiment, and for rethinking how human and non-human actors co-produce each other. While the ontology of conventional cyborgs

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is equal only to the material sum of its parts, in Haraway’s cyborg, the parts potentiate each other. Human bodies are viewed as dynamic complexities of flesh, mechanical circuitry, cultural and technical discourses, practices, ideas and material objects. According to Haraway, the blurred boundary between human and machine exists on two ontological levels: the first, the cyborg of “social reality” is the material cyborg which is “configured via military-industrial entertainment complex: the cyborg of science fiction films, the warrior macho human-machine, the medicalized body that is normalized by technologies and earns profits for pharmaceutical and medical device companies.”

37 The second type of cyborg body is the “creature of fiction,” which refers to a metaphorical cyborg: “the figure that challenges assumptions and binaries, that is politically disruptive, progressive and oppositional in its hybridity and liminality.”

The material cyborg

Scholars have interrogated the cyborg of social reality, the “material cyborg,” by investigating questions of material subjectivity, social relationality, and embodiment with respect to biotechnologies including external medical devices (i.e. insulin pumps), prosthetics, heart pacemakers, and kidney dialysis machines.  

37 Lupton 2013, p. 5  
38 Lupton 2013, p. 5  
One prominent theme that has been discussed in cyborg literature regards the way in which new human-biotechnology entanglements have transformed how patients and clinicians view issues of agency, responsibility, and ownership. The intended function of replacement cyborg technologies is to mediate physiological equilibrium within a body without requiring patient consciousness or intervention. However, several scholars have illuminated how minimizing the patient’s role in their disease management has important consequences on the quality and efficacy of their care.\(^\text{40}\) Notable works include Nelly Oudshoorn’s interrogation on the materiality of the cyborg experience of patients who have pacemakers and implantable cardioverter defibrillators (ICDs).\(^\text{41}\) She contends that the cyborg experience “may involve conflicts between the agencies of bodies and internal devices as well as struggles between different ways of knowing hybrid bodies.”\(^\text{42}\) The patient, technician, and physician each see the body through different gazes, which are inextricably linked to particular ways of knowing and experiencing the body. However, some gazes are prioritized more than others. For patients who have internal devices, including machines and medications, their voices and lived experiences are particularly negated because they do not have the ability to control the technological output. Oudshoorn describes how technicians rely on data produced by the ICD programmer in order to

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\(^{41}\) Oudshoorn 2015, “Sustaining cyborgs”

\(^{42}\) Oudshoorn 2015, p. 57
make mechanical adjustments. Meanwhile the patient’s sensory experiences are ignored as unimportant to the maintenance of the device. In reality, the patient has an understanding of the device functioning based on their sensory perception of the implanted device itself. This tacit, embodied knowledge is extremely important to how effectively the device is functioning, including the validity of the output.

Another important concept evoked by the material cyborg regards the role that a patient’s attitude towards their cyborg technology plays in informing their sense of identity and empowerment surrounding this entanglement. This was exemplified by a study conducted by Rhonda Shaw, who examined how the concepts of hybrid embodiment and material cyborg identity can be used to better understand the lived experiences of at-home kidney dialysis users. Shaw conducted 24 in-depth interviews with kidney dialysis users that were guided by four phenomenological themes: lived body (corporeality), lived time (temporality), lived space (speciality), and lived relation (relationality). Shaw’s interviews focused on how these patients perceived their relationships to their dialysis machines, and how the newfound human-machine entanglements disrupted their qualities of lives and transformed their senses of identity. Of note, most dialysis patients reported reduced quality of life due to a perceived loss of independence as well as an inhibited ability to work and participate in leisurely activities. Many voiced a preference for home dialysis compared to hospital dialysis because it provided them with more temporal and spatial freedom, and spared them from taking on a “sick patient” role. However,

home dialysis machines often required patients to change the spacial arrangements of their homes, which consequently influenced their relationship to their home and to family members/spouses sharing the space. The most empowered patients all spoke to the importance of not treating their dialysis machine as a foreign intruder, but rather as an integrated part of their beings that helps them to live and thrive. Shaw further emphasized the importance of patients embracing their new cyborg identities, and that patient empowerment requires users to undergo an attitude shift towards their machines and towards their interpersonal support systems.

Other scholars have used the material cyborg to ground their arguments about the implications of human-machine fusions for creating new meanings and interpretations of bodily truth and ontology. Haraway asks, “Why should our bodies end at the skin, or include at best other beings encapsulated by the skin?” Human entanglements with medical biotechnologies have broadened the borders of the treatable body, past the skin and onto digital computer screens displaying numerical data output. The underlying algorithms that run internal and external health surveillance devices and associated computer programs, have produced a new bodily “truth”—a new way of seeing the internal state of the cyborg body through the “technician’s gaze.” To “gaze” into a body refers to a process of selectively deciding which pieces of information in a data stream is most important to decision making, both consciously and unconsciously. The technician’s gaze is based on Foucault’s concept of the medical gaze, which describes the process by which physicians

44 Haraway 2000, p. 314
selectively filter out aspects of the patient’s narrative that do not fit into a biomedical framework. Through the technician’s gaze, technicians and clinicians understand the patient’s body and make treatment decisions based on technical data output without any deference to non-technical aspects of the patient’s lived experience and disease embodiment.

According to Nelly Oudshoorn, the technology-mediated gaze of the technician is highly entangled with patients’ own ways of gazing into their bodies. As patients become increasingly in tune with their hybrid bodies, they start to integrate the auditory and visual output of their devices with their subjective sensations and interpretations of bodily symptoms. The co-constitutive relationship between technical data output and subjective experience is a core characteristic of modern day medical cyborg bodies. Deborah Lupton encapsulates this phenomenon through the “digital cyborg assemblage,” which she defines as a “modern cybernetic body that is configured and understood by data and self-knowledge.” To reiterate, modern day human-biotechnology entanglements are not just characterized by the material fusion of flesh with machine parts. Rather, the cyborg’s ontology can be understood as what Haraway describes as a combination of “text, machine, body, and metaphor – all theorized and engaged in practice in terms of communications.” Cyborg identities are formed as a patient’s cultural and medical belief systems engage with biotechnical markers and quantitative values such as cholesterol, blood pressure, blood glucose

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46 Misselbrook 2013, “Foucault”
and weight. The technician’s objective markers and the patient’s subjective experiences are reconciled through practices of communication between the parties.

The metaphorical cyborg

The second type of cyborg body that Haraway describes is the “creature of fiction”, which refers to a metaphorical cyborg: the figure that challenges assumptions and binaries, that is politically disruptive, progressive and oppositional in its hybridity and liminality.\(^{48}\) Aside from the dualism between human and machine, Haraway illuminates other dualisms signified by the metaphorical cyborg, that are also in the midst of a “border war”: self/other, material/non-material, mind/body, culture/nature, male/female, civilized/primitive, reality/appearance, whole/part, agent/resource, maker/made, active/passive right/wrong, truth/illusion, total/partial, God/man.”\(^{49}\) From the second we are born, these dualisms are programmed into us through media, social learning, medical interactions, and the state, amongst many other programming networks. Binaries are such hegemonically entrenched parts of our lives that at times they feel as natural and necessary as breathing or eating. This illusion of naturalization fuels binaries as sites of domination. Haraway claims that “certain dualisms have been persistent in western traditions; they have all been systemic to the logics and practices of domination of women, people of color, nature, workers, animals—in short, domination constituted as others, whose task is to mirror the self.”\(^{50}\) The metaphorical cyborg challenges dominant structures of knowledge

\(^{48}\) Lupton 2013, p. 5
\(^{49}\) Haraway p. 313
\(^{50}\) Haraway p. 313
production and application, as well as challenging social institutions of racism, heterosexism, and misogyny that created the illusion of the ontologically stable binary categories in the first place. When we forget that binaries are politically and socially constructed, we cease to remember our agency to deconstruct and consequently resists oppressive regimes. Haraway reiterates this when she argues for “pleasure in the confusion of boundaries and for responsibility in their construction.”

Not many scholars have used the metaphorical cyborg for analyzing potential political implications of human-biotechnology entanglements. Of note, Bradley Lewis used the cyborg as a political agent that symbolizes the urged dissolvement of the boundary between dominant forms of psychiatric knowledge and alternative forms of knowledge. The entanglement that Lewis speaks of is a systemic entanglement between the clinicians/practices of biomedicine and corporate pharmaceuticals who produce the technoscientific innovations.

**Biomedicalization**

Biomedicalization is a theoretical framework that describes the process by which medical phenomena, humans, and non-human bodies are transformed through the use of technoscientific innovations such as molecular biology, biotechnologies, genomics, transplant medicine, and new medical technologies. Cyborg technologies

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51 Haraway 2000, p. 293
and associated human-machine bodies were born from five interactive processes in which biomedicalization manifests. I specifically focus on modern day cyborg features that exemplify the following three biomedical processes: 1) the focus on health itself and elaboration of risk and surveillance biomedicines; and 2) transformations of biomedical knowledge production, information management, distribution and consumption; and 3) transformations of bodies to include new properties and the production of new individual and collective technoscientific identities.54

Unlike its predecessor framework, medicalization, biomedicalization not only describes the process by which illness, disease and injury are classified and treated, but also how health and risk are conceptualized and addressed—specifically through technoscientific interventions. Under biomedical processes, the prevailing knowledge base is used to assess risk and justify the need for surveillance technologies. In turn, these surveillance technologies produce more precise data that reinforce the importance of utilizing surveillance technologies. The subsequent surveillance leads to even more precise algorithms which, in a feedback loop, reinforce the need for further surveillance. The construct of risk has drastically transformed conceptions of health by eliminating the concept of normalcy altogether. For instance, Clarke et al states “it is no longer necessary to manifest symptoms to be considered ‘at risk’ and “under surveillance medicine, everyone is implicated in the process of eventually ‘becoming ill.”55

54 Clarke et al 2010, p. 49
55 Clarke et al 2010, p. 64
The promotion of risk status as the new definition of health has created new meanings of personhood through a biomedical practice called personalized medicine. Personalized medicine is grounded in the idea that every individual has a distinctive genetic profile, family history, and environmental background and thus, trends of disease onset, presentation, and treatment cannot be generalized to a whole population.\(^{56}\) Rather, personalized medical procedures involve the stratification of individuals into distinctive risk categories and treatment groups based on the evaluation of their genomic profile.

In their piece, “Genetic Risk and the birth of the somatic responsibility,” Carlos Novas and Nikolas Rose describe the social implications of a new personalized medical procedure called “genetic risk assessment.”\(^{57}\) Using highly complex computer programs, algorithms, and gene mapping technologies, researchers can now “characterize genetic sequences or markers associated with the occurrence of many conditions at the molecular level.”\(^{58}\) With a simple blood test, an individual’s genetic profile can then be compared to these pre-established algorithms and consequently stratified into “at-risk” disease categories. In this procedure, life is “now imagined, investigated, explained, and intervened upon at a molecular level—in terms of the molecular structure of bodily components, the molecular processes of life functions, and the molecular properties of pharmaceutical products.”\(^{59}\) As this


\(^{58}\) Novas and Rose 2000, p. 486

\(^{59}\) Novas and Rose 2000, p. 487
paradigm is communicated to patients, they internalize these technological, genomic constructs in a way that transforms their personal identities. People reform their lifestyles in accordance with these new technoscientific identities based on risk status (i.e. exercising more, taking vitamins, going in for routine check ups). New social and medical identities are also constructed as individuals develop a conception of their personhood that is based around quantitative biometric data (i.e. blood pressure and cholesterol counts) and molecular, genomic markers (i.e. being a carrier of the BRCA breast cancer gene). Carrying these risk factors may change the way an individual navigates social relationships, activities and future planning.

Finally, as technology continues to evolve and new pharmaceutical products are developed, quantitative and algorithmically conceptualized measures of pathology are brought into the treatment-decision model under the goal of providing patients with an ostensibly “objective” representation of their disease/risk state that will make them more receptive to a treatment plan based around pharmaceutical intervention. The objective data that are used to operationally define risk status have now become endpoints for health and quality of life. The focus on these objective endpoints has had two major implications on how clinical care is addressed. First, these endpoints have shaped how clinicians define and address quality of life (QOL). In a biomedical framework, QOL is systematically operationalized as the management of quantitative biometric risk factors. Consequently, the patient’s subjective interpretation of QOL is minimized in favor of objective markers. Second, the promotion of objective

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endpoints may perpetuate health inequality and discrimination as they provide clinician’s with a structural justification to “listen” to the numbers at the expense of ignoring the the lived experiences and health belief systems of their patients. This would have particular impact on marginalized populations who have historically disproportionately been dismissed in clinical settings.61

Finally, biomedical processes are marked by the transformation of medical knowledge distribution which is associated with a transformation in the roles that physicians and patients have in decision making practices. Historically, physicians were the exclusive keepers of medical knowledge in the clinical setting, and would make most executive decisions with respect to disease management.62 In many ways, clinicians’ monopoly on knowledge and control has been exacerbated under biomedical processes, as technologies such as computer data management and genomic software systems require specialized knowledge that relatively few professionals, and certainly few lay people hold. Klugman articulates the transforming roles and responsibilities of clinicians in this digital age:

These complex, integrated devices require an intermediary to make the minute and tedious connections between the human bodies and the machine parts. Since medical practitioners are already experts in autonomy and physiology, they are the obvious choice to serve in this capacity. Thus, physicians function as gatekeepers in determining which human-machine connections to permit

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62 Clarke et al 2010, p. 73
and to develop. Should a certain machine be implanted? Should a particular technology be developed? Facilitators of the human-machine interaction face new choices, new responsibilities, and new patients. Some of the technologies are so recent that there are no real world guides.\textsuperscript{63}

As physicians increasingly assume the role of “middleman” between machine (biotechnology) and patient, their responsibilities are transformed as they develop a common language to translate the methodologies and results produced by the machines, into concepts that are accessible to the layperson. The most salient aspects of physicians’ responsibilities affected by medical technologies are treatment, experimentation, conflict of interest, informed consent, new disease, and medical norms.\textsuperscript{64}

Paradoxically, however, the biomedical technoscientific age has also been marked by improved patient access to knowledge (i.e. via internet services), self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self help services. These new services have transferred responsibility from the professional physician/provider to include collaboration with or reliance upon the individual patient/user/consumer.\textsuperscript{65} Thus, the shared decision making model potentially can be a source of increased collaboration but can also be a source of increased tension and conflict. Understanding the implications of biomedical knowledge distribution systems on the professional—patient chasm requires an understanding of the delicate tension between newfound modes of bodily control and

\textsuperscript{63} Klugman 2001, p. 2
\textsuperscript{64} Klugman 2001
\textsuperscript{65} Clarke et al 2010 p. 65
power exerted by clinicians and technicians, and newfound embodiments of empowerment and agency internalized by patients and caregivers. The shift in these tensions is emblematic of the broader power shift in the doctor-patient relationship, and the tug of war battle each party engages in with each other.
Chapter 2: Treating IBD Cyborg Bodies using
Shared Decision Making Practices

In a speech delivered by a prominent Inflammatory Bowel Disease (IBD) specialist, Dr. Marla Dubinsky, at a Los Angeles Crohn’s and Colitis fundraising event, Dubinsky stated, “Twenty years ago, we had only two really good treatment options, and in the next five, years there’s probably going to be up to five new treatment options. Truth be told, as we’re heading in this direction, we’ll be able to say: Jennifer this is your treatment. John this is your treatment. Bob this is your treatment; we’re really getting closer to personalizing and individualizing treatment.” As echoed by Dr. Dubinsky, the (pharmaceutical) medication options available for IBD patients have drastically improved in the past fifty years, resulting from the emergence of important developments in knowledge regarding IBD’s pathogenesis, coupled with a recent surge of interest from Big Pharma to invest in therapies grounded in the personalized medicine paradigm. When Crohn’s disease was first discovered, very little was known about the pathogenesis of CD and UC. Consequently, treatment options were limited to surgical resection, antibiotics and diet. Around 1950, gastroenterologists and researchers developed an understanding that IBD resulted from autoimmunity and consequently could be treated with immunosuppressant drugs.68

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66 Names have been changed.
In this chapter, I argue that a chasm has emerged between the doctor’s gaze and the IBD patient’s lived experience due to physicians’ failure to view IBD patients as IBD cyborg bodies. That is, clinicians tend to view IBD drug therapies as discrete, neutral agents that act materially on a patient. This conceptualization of biologics has driven the development of several other associated IBD biotechnologies. Notably, a drug surveillance assay that monitors a patient’s serologic drug levels has been used to guide decisions about drug use and dosing through a paradigm called therapeutic drug monitoring (TDM). In tandem with its associated drug, TDM surveillance technologies produce quantitative data points that have influenced communication and decision making practices between doctor and patient, as well as shaped the patient’s interpretation and experience of their own bodily symptoms.

In this chapter, I conduct a series of discourse analyses of patient blog posts and clinician-authored biomedical research studies and statements, in order to compare the physician’s “cyborg-less” understanding of the drug-patient relationship with the reality of the patient’s material, social and psychological entanglement with biologic drugs. Then, I focus on another biotechnology entanglement that has emerged between the patient’s interpretation of symptomatology and the digital output of the TDM surveillance technologies. I use the concept of the cyborg to explore how these technologies have expanded the boundaries of the IBD patient’s treatable body, past the skin and onto digital platforms to be gazed at and analyzed from a distance by the clinician. Finally, I analyze shared-decision making discourse to illuminate how the principle of risk is used by clinicians in order to encourage patients to consent to using biologic therapies early after diagnosis as part of the top-
down treatment model (which I will elaborate on). I center all of these analyses around the following question: what has been lost in techno-translation as a patient’s bodily truth is translated into highly precise, quantitative assessment criteria? How have these endpoints shaped how treatment decision making conversations unfold in the clinic, and transformed the power imbalance embedded in the doctor-patient relationship?

*Overview of Inflammatory Bowel Disease (IBD)*

Inflammatory Bowel Disease (IBD) is an umbrella for two digestive diseases: Crohn’s disease (CD) and ulcerative colitis (UC). Currently, there are approximately 1.6 million Americans who have CD or UC and as many as 70,000 new cases of IBD are diagnosed in the United States each year. Historically, IBD has been most prevalent in developed countries, especially in urban areas, though this disease pattern has gradually shifted. Although IBD can afflict an individual at any age, people are most frequently diagnosed with IBD between the ages of 15 and 35. IBD affects all genders equally. The etiology of IBD has been widely contested among clinical providers and researchers. While still not definitive, many speculate it to result from the intersection of a patient’s environment, genomic and microbial

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71 “The facts about Inflammatory Bowel Disease.” *Crohn’s and Colitis foundation.* Published November 2014.
composition, and demographic variables. Notably, a myriad of risk factors have been associated with the onset of IBD including smoking status, antibiotics use, nonsteroidal anti-inflammatory drugs, appendicitis, and diet.\textsuperscript{72} Several genes have also been connected to IBD, such as the NOD2/CARD15 gene (for CD).\textsuperscript{73} It is important to understand that neither environmental nor genomic risk factors are predictive of disease diagnosis. In fact, many individuals with these markers do not develop IBD and conversely, many patients with IBD do not possess these variables. Still, clinicians and researchers are using many of these factors as the basis for disease subtyping/classification, treatment development, and decision making.

Both Crohn’s disease and ulcerative colitis are characterized by chronic inflammation and damage in the gastrointestinal (GI) tract. However, whereas Crohn’s disease can present anywhere in the digestive system, ulcerative colitis disease presentation is localized to the large intestine (the colon) and the rectum.\textsuperscript{74} CD and UC are further distinguishable by the fact that UC only produces inflammation and ulceration on the outermost layer of the intestinal lining (the epithelial lining), whereas Crohn’s disease inflammation and ulceration is often transmural, meaning it pervades the full thickness of the bowel wall. IBD is

\textsuperscript{72} “The facts about Inflammatory Bowel Disease” 2014, 9
\textsuperscript{74} Crohn’s Disease can present anywhere in the digestive tract including: the oral cavity (mouth) esophagus, liver, stomach, small intestine, terminal ileum, large intestine (colon), rectum, and anus, but most commonly affects the terminal ileum, which is the last part of the small intestine. Ulcerative Colitis only presents in the colon and rectum, and only affects the epithelial lining of the mucosa. CD patients experience extraintestinal symptoms, such as joint pain and skin lesions/rashes, more often than UC sufferers.
characterized by a myriad of clinical gastrointestinal symptoms including: severe abdominal pain, diarrhea (presenting with or without blood,) nausea, vomiting, and constipation, as well as a host of extraintestinal manifestations such as joint pain, weight loss, fatigue, fever, eye inflammation and skin complications (i.e. erythema nodosum). Upon diagnosis, Crohn’s Disease patients may also present with serious structural intestinal complications including anal fissures, fistulas, bowel obstruction, structuring, and perforation, most of which require immediate surgical intervention. IBD presentation is incredibly heterogeneous in nature in that disease manifestation may differ greatly between two CD or UC patients, let alone between the two sub-diseases. This heterogeneity poses a challenge for clinicians to make appropriate disease diagnosis and treatment decisions.

IBD was first described by Drs. Crohn, Ginzburg and Oppenheimer at the Mount Sinai Hospital in 1932. In their seminal paper published in the Journal of the American Medical Association (JAMA), Crohn et al described a phenomenon called *regional ilieitis*, “a disease of the terminal ileum, affecting mainly young adults, characterized by a subacute or chronic necrotizing cicatrizing inflammation.”

Symptoms included “fever, diarrhea, and emaciation, that eventually lead to an

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76 Anal fissures are tears that merge in the thin moist mucosa of the anus. A fistula is an abnormal connection between two hollow spaces (i.e. the intestine and the vagina). A bowel obstruction forms when the intestine is fully or partially blocked, from food or from a structural malformation. A perforation is a hole in the intestinal wall that forms from chronic inflammation. A stricture refers to the narrowing of a section of intestine caused by scarring, which can lead to intestinal blockage “What are the symptoms of Crohn’s Disease,” 2016.
obstruction of the small intestine; the constant occurrence of a mass in the right iliac fossa usually requires surgical intervention...The terminal ileum is alone involved.”

When Crohn et al devised this first conceptualization of IBD (“regional ileitis”), most medical disciplines at the time were driven by rudimentary disease classification, diagnoses, communication and treatment methods. As evidenced above, classifications of pathology consequently relied on clinical phenotype (i.e. overt symptom presentation) to describe the multitude of disease manifestations. Furthermore, due to a lack of available precise treatment options, therapeutic intervention was grounded in a “therapeutic nihilism between surgical episodes.”

Thus, whereas Crohn et al’s observations of “obstruction,” and “iliac mass” were initially presented as essential disease characteristics, today they would be viewed as preventable complications. Similarly, surgical intervention is no longer seen as an inevitable requirement. With current available treatment options, it is rather viewed as merely one therapeutic possibility, if not a last resort.

**Evolution of IBD Diagnostic Tools**

Since 1932, IBD management has evolved as new technoscientific diagnostic tools, online communication portals, and personalized pharmaceutical drugs have infiltrated clinical practice. Today, clinical phenotypic presentation is no longer sufficient to make an official diagnosis. Suspected patients now undergo a series of

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highly advanced, relatively painless endoscopic, radiologic and histologic procedures including standard imaging procedures such as colonoscopy, endoscopy, MRI/CT of the abdomen, and transabdominal/rectal endoscopic ultrasounds which identify the severity and location of inflammation, ulceration, and other complications. In the past five years, novel non-invasive imaging techniques including virtual colonoscopy/Entero CT, and wireless capsule endoscopy have been employed as well.\textsuperscript{79}

In addition to imaging tests, clinicians conduct a myriad of blood and stool tests that identify and measure specific biomarkers that serve as proxies for source and extent of systemic inflammation. While there is no definitive diagnostic blood test, elevated leukocyte, thrombocyte and acute phase biomarkers such as C-reactive protein are indicative of chronic intestinal inflammation. Histologic interrogations of bacteria, virus, parasites and C difficile toxin from stool are also used to indicate and differentiate IBD from other intestinal diseases.\textsuperscript{80} Finally, in synchrony with that of other biomedical fields, the future of IBD diagnosis will utilize genomic markers and gene identification as driving criteria for disease classification. Several genome-wide association studies have been conducted that have already identified over 160 genes associated with IBD.\textsuperscript{81}

\textsuperscript{79} Wireless capsule endoscopy is a simple radiation free method in which patients swallow a capsule that contains a videochip, transmitter and small battery. The ingested capsule remotely transmits photographs of the upper GI mucosa to a portable device carried by the patient; Nikolaus, Susanna and Stefan Schreiber. “Diagnostics of Inflammatory Bowel Disease.” \textit{Gastroenterology} 133, no. 5 (2007): 1678-1780

\textsuperscript{80} Nikolaus and Schreiber 2007, “Diagnostics of Inflammatory Bowel Disease,” 1674

\textsuperscript{81} Nikolaus and Schreiber 2007, “Diagnostics of Inflammatory Bowel Disease,” 1684; “The facts about IBD”, 2014, Crohn’s and Colitis foundation, 2
The ultimate goal for IBD diagnosis is to create a codified, standardized system that will synthesize data from genomic, histologic, serum, imaging, and clinical assessments, in tandem with demographic data (i.e. weight, gender, race, age, and smoking status), to precisely identify a patient’s disease type, and consequently, stratify them into the most appropriate personalized pharmaceutical treatment or surgical pathway. As IBD diagnosis becomes increasingly driven by genomic data, disease categorization may expand beyond that of the prevailing binary of “Crohn’s disease” versus “ulcerative colitis.” Rather, disease classification would result from a more nuanced, multifaceted integration of demographic variables combined with the assessment of three domains of disease severity: impact of the disease on the patient (quality of life, clinical symptoms, and disability), measurable inflammatory burden (C-reactive protein, mucosa lesions, upper gastrointestinal involvement and disease extent), and disease course (including structural damage, history/extension of intestinal resection, number of flares, extraintestinal manifestations, etc). In an article published in 2003, Arnott and Satsangi further explain this evolving disease stratifying phenomenon: “A number of attempts have been made to subclassify patients with Crohn’s disease into subgroups with similar stable phenotypic characteristics. These attempts have been catalyzed first by attempts to individualize therapy, and most recently progress in understanding the molecular genetics of Crohn’s disease, and the need to relate genotype to disease phenotype.”

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This statement points to an important paradigm which is at the heart of IBD clinical practice, regarding the synergistic relationship between modern taxonomical systems, personalized genomic models of etiology, and treatment development practices. As two key sites of biomedical processes, diagnostic technologies and medications co-constitutively inform the personalized nature of each other as well as the lived experience of the observed patient. Thus, the trend towards specificity and personalization elicited by IBD classification technologies is mirrored by that in medication development.

Review of IBD Medications

For the second half of the 20th century, IBD medical management was centered around four broad drug categories: corticosteroids, aminosalicylates, antibiotics, and immunomodulators. While all elicited various extents of clinical relief, each respective pharmacokinetic mechanism and metabolism posed clinical challenges to doctors and patients alike. For example, corticosteroids (i.e. prednisone) are only effective for short-term control of flare-ups due to their dangerous side effects including infection, bone loss, weight gain and mood swings. Aminosalicylates, which are anti-inflammatory compounds that contain 5-aminosalicylic acid, were limited to decreasing inflammation only at the intestinal wall, and thus are primarily effective in treating UC but not CD. Out of the four treatment categories listed above, immunomodulators, which include azathioprine, 6-mercaptopurine, and methotrexate, are the most systemic and work to modify the

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84 “The facts about IBD”, 2014, Crohn’s and Colitis foundation.
activity of the immune system by inhibiting lymphocytic proliferation. This systemic mechanism of action makes immunomodulators more clinically effective than the latter two and are generally prescribed in patients who failed other medications (other than steroids).\textsuperscript{85} However, immune modulation poses a series of serious physiologic risks including nausea, infection, itching, liver damage, and increases your risk for developing lymphoma.\textsuperscript{86} The biggest limitation of all these medications is that none fully heals the intestinal mucosa. Consequently, patients are left at risk to develop complications resulting from chronic inflammation, scar tissue, and other structural damage.

In 1998, a new class of drugs, called biologics, entered the clinical landscape and revolutionized IBD treatment and practice. Biologics is a broad drug class that work by binding to (and de-activating) specific proteins known to activate autoimmune responses, rather than modulating a more generalize immunological pathway (as do immunomodulators). The first biologic drug made available for IBD management was called Infliximab. Released by Janssen Pharmaceuticals in 1998, Infliximab, colloquially called “Remicade,” is part of a class of biologic drugs called anti-Anti-Tumor necrosis factor (TNF) agents, which are bioengineered agents that bind to the TNF protein that plays a huge role in inflammatory responses. Compared to the other drug classes described above, infliximab was the first IBD therapy that works to fully heal the mucosal lining and change the natural history of the disease—the latter referring to the drug’s ability to prevent a patient from eventually

\textsuperscript{85}“The facts about IBD”, 2014, Crohn’s and Colitis foundation.
\textsuperscript{86}“Immunomodulators for Inflammatory Bowel Disease.”\textit{WebMD.com}. Last updated November 14, 2014.
experiencing penetrating or stricturing complications leading to repeated surgeries and disability.\textsuperscript{87} Since infliximab’s release twenty years ago, three other anti-TNF biologics have entered the market for IBD treatment: adalumimab (“humira”), (approved in 2007 for CD), certolizumab (approved in 2008 for CD), and golimumab (approved in 2013 for CD). These drugs have demonstrated to be the most clinically effective drugs available, and notably, also the most lucrative. In 2015, Janssen’s Remicade and Abbvie’s Humira made $6.6 billion and $14 billion\textsuperscript{88} respectively.\textsuperscript{89} As personalized medical treatments have gained traction in medical practice, pharmaceuticals have increasingly invested in developing drugs to target other specific biological pathways, other than TNF. Notably in 2014, the US Food and Drug Administration (FDA) approved Takeda Pharmaceuticals vedolizumab (“Entyvio”), a monoclonal antibody that binds to the integrin $\alpha_4\beta_7$ inflammatory protein. Most recently, Janssen released ustekinumab (“Stelara”), a biologic that targets interleukin (IL) 12 and IL-13, other extremely important actors in the auto-inflammatory cascade.

According to the FDA, infliximab and adalumimab are indicated for patients with Crohn’s disease and Ulcerative Colitis who have “had an inadequate response to

\textsuperscript{87} Golovics, Petra, Michael Mandel, Barbara Lovasz and Peter Lakatos, “Inflammatory Bowel disease in Crohn’s disease: Is the natural history changing?” \textit{World J Gastroenterology} 20, no. 12 (2014):3198-3207


\textsuperscript{89} Abbvie’s Humira is currently the top-selling drug in the world. Aside from IBD, it is also used to treat many other autoimmune diseases including juvenile arthritis, psoriasis and ankylosing spondylitis.
conventional therapy” (referring to the other four classes of drugs).\textsuperscript{90} When infliximab was first introduced to the field, most clinicians followed this guideline as part of a broader prevailing treatment paradigm called “step-up.” Step-up therapy refers to a sequential treatment strategy in which clinicians first prescribe the least aggressive, arguably safest drugs (i.e. antibiotics, aminosalicylates, budesonide), then escalate to more effective, but notably more toxic treatments such as immunomodulators, and finally, if a patient has clinically failed the latter options, prescribe biologic therapy.\textsuperscript{91}

Historically, the step-up therapy model has dominated IBD practice due to concerns of the adverse side effects and financial costs of immunomodulators and biologics. This strategy addresses clinician and patients’ fears by avoiding overtreating and unnecessarily exposing patients to adverse risks of toxicity, especially in patients who respond well to antibiotics and aminosalicylates. In the past few decades, however, many studies have revealed a major shortcoming of step-up therapy; that is, most patients treated with the step-up therapy paradigm eventually develop stricturing or penetrating disease, as well as other secondary disease complications such as chronic fatigue, joint pain and eye inflammation.\textsuperscript{92} Based on these results, step-up’s antithesis paradigm, called “top-down” therapy, has increasingly been touted by clinician experts as the superior treatment model.\textsuperscript{93}

\textsuperscript{90} “Inflximab: Highlights of Prescribing Information.” FDA.
\textsuperscript{92} Lin 2010
\textsuperscript{93} Dubinsky, Marla. “Role of TNF-alpha inhibitors.” MD Magazine. Video. 18 December 2017.
top-down therapy approach, biologics and immunomodulators are prescribed (as mono or combotherapy) as the first line of therapy for patients with moderate to severe disease. Several studies have shown that early aggressive treatment with these medications lead to longer-sustained remission in children with early CD, internally heal fistulas (thereby eliminating need for surgery) and prevent irreversible mucosal damage, thereby changing the natural history of the disease.94

However, despite data supporting the clinical efficacy of the top-down model, many patients feel and express great ambivalence about starting biologic or concomitant biologic-immunomodulator therapy due to these drugs’ wide set of associated deleterious side effects including increased risk of infection, shortness of breath, psoriasis, and lymphoma.95 The therapeutic drug decision is a primary source of disagreement between clinicians and patients. Consequently, in the past decade there has been a surge of commitment from clinicians to develop better methods for communicating the risks and benefits of biologics and immunomodulators.96 Shared decision making practices in the field of IBD largely revolve around educating and making patients more comfortable around consuming these drugs.

*The Role of IBD Cyborg Patients in Shared Decision Making (SDM) Practices*

Dr. Corey Siegel, a prominent IBD expert, recently summarized clinician goals for SDM conversations with patients:

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94 Lin, Blonski, and Lichtenstein 2010, “What is the Optimal Therapy”,
We are moving from a time when the standard of care appeared to have been providing safe and effective treatment, to an era where maximizing treatment response may be possible, but will require patients to make preference-sensitive decisions. A preference-sensitive decision means that there is more than one appropriate treatment choice, and patients will agree on what is right for them based on how they value benefits versus harms. Their choice for treatment will depend upon their optimism of response, aversion to risk, severity of illness, tolerance of symptoms and, importantly, what they learn about these treatments from doctors, friends, advertising and the internet.97

Dr. Siegel’s statement illuminates several notable themes regarding gastroenterologists’ understanding of the patient’s relationship with biologic drugs. As referenced in this quote, IBD clinicians almost exclusively describe patient beliefs and concerns about biologics with respect to how they fear and weigh adverse side effects against their belief in the therapy’s efficacy. Indeed, this understanding is based on patient surveys and physicians’ clinical experiences, and fear of biologic side effects is certainly a prevailing concern amongst most patients and caregivers. However, there are certain focal aspects of a patient’s relationship to biologic drugs that doctors like Siegel fail to critically examine in questionnaires and address in practice—certain critical nuances of the patient-drug entanglement that escape the clinician’s gaze. Biomedical clinicians illusorily view IBD drug therapies as discrete, neutral agents that act materially on a patient. This conceptualization of biologics has driven the development of several other associated IBD biotechnologies. Notably, a

97 Siegel, 2010, “Making Therapeutic Decisions”
drug surveillance assay that monitors a patient’s serologic drug levels has been used to guide decisions about drug use and dosing through a paradigm called therapeutic drug monitoring (TDM). In tandem with its associated drug, TDM surveillance technologies produce quantitative data points that has influenced communication and decision making practices between doctor and patient, as well as shaped the patient’s interpretation and experience of their own bodily symptoms.

Under cyborg theory, the reality is that IBD drug therapies, diagnostic technologies, TDM drug surveillance tools, and communication technologies inform and are informed by two separate, albeit overlapping dialectical cyborgian relationships: 1) these biotechnologies act (and are acted upon) by the patient’s lived experience, priorities and belief systems; and 2) they act (and are acted upon) by the physician’s end goals, etiology models and interpretation of their quantitative, ‘objective’ metric systems. Figure 1 illustrates the positionality of several important variables in the tug of war battle that manifests between doctors and patients in IBD decision making practices. I offer this as a visual representation of the dialectical relationship between the clinician/technician’s gaze and the patient’s subjective interpretation of biotechnical endpoints. Of note, I do not intend for this to be read literally as a schematic design, but rather as a visual aid to accompany my prosaic description.
Figure 1: Visual flow chart illustrating the causal relationality between disease etiology models, personalized objective endpoints, surveillance technologies, and patient/clinician interpretation of distant data.

In this model, the biologic drug produces “objective” endpoints that are used as the basis for designing drug and disease surveillance systems. Note how the distant data produced by the drug and disease surveillance technologies serve as a point of tension in this pathway, whereby the patient’s interpretation of data and consequent perceived experience of symptoms pull away from the physician’s interpretation of data and consequent drug dosing and selection decisions.

The data produced by the surveillance systems inform (and often conflict) with the patient’s lived experience/perception of symptoms. In turn, the patient learns to perceive their symptoms in relation to their material drug consumption and the data it produces. Understanding the social and material mechanisms by which IBD biotechnologies act in this process is crucial for better understanding (and ultimately, mitigating) this clinical tug of war battle. How does clinicians’ lack of cyborg
thinking manifest in their promotion and interpretation of “objective” endpoints?
How are these endpoints (which notably, are produced by the drug itself) limited with respect to their inability to capture the totality of a patient’s lived experience? What is lost in the technological translation of bodily experience to biometric data? How is a patient’s perception of their bodily integrity and symptoms influenced by their knowledge of quantitative data regarding their drug metabolism and disease state?
How is the clinicians’ approach to risk interpretation and stratification epistemologically related to their inability to see the cyborg body? What implications does this have for the doctor-patient relationship, and more broadly for the operation of SDM? In the following sections, I address these questions through discourse analyses of patient blogs, clinician-authored publications, and evaluations regarding SDM practices.

_The IBD Patient and Biologic Drug Entanglement_

In the past twenty years, since the introduction of Infliximab in 1998, biologic drugs have pervaded the field of IBD and helped thousands of people gain unprecedented relief from excruciating pain, embarrassing symptoms, and debilitated quality of life. In the process, however, these drugs have transformed doctor-patient clinical encounters by influencing doctors’ priorities for patient treatment/care in ways that differ from that of the patient. This consequence has important implications for decision making practices and health outcomes. In this section, I will use a cyborgian understanding of the body to illuminate the facets of the patient’s material, social, and psychological entanglement with biologic drugs, as demonstrated in
patient blog posts from a public online support forum called *crohnsforum.org*. I will be specifically focusing on discourses surrounding Jansen Pharmaceutical’s infliximab, as infliximab (“Remicade”) has been clinically used for the longest time, and thus researched and written about more than the other IBD biologics.

Infliximab is a chimeric monoclonal antibody that targets tumor necrosis factor (TNF), a protein that is heavily involved in immune responses against viruses, bacteria, fungi, and other pathogens. The concept of developing an anti-TNF agent for IBD treatment followed research that identified TNF as an overly produced auto-immunological player in actively inflamed mucosal tissue in individuals with IBD. Through binding and deactivating TNF in inflamed areas, infliximab induces both clinical (symptomatic) and histologic (microscopic) remission in suffering individuals. As a chimeric antibody, infliximab is produced from mouse cells that are engineered to make human-like antibodies; consequently, the drug is comprised of approximately 30% murine (mouse) and 70% human DNA. While the human immune system is designed to respond against any recognized foreign material, infliximab’s murine component particularly puts patients at risk for developing “immunogenicity” against the drug, a phenomenon that manifests when a patient’s immune system recognizes Infliximab as foreign and develops antibodies against the drug, itself. Immunogenicity reactions are not only scary to experience but also severely reduce the efficacy of the drug. In tandem with immunogenic reactions,

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98 “How Biologic Drugs are Made.” *blog.chronology.com*. Last modified October 8, 2015.

99 Immunogenic reactions usually occur during the intravenous infusion. The most common symptoms of immunogenicity include itchiness and redness on the face and by the IV site, as well as shortness of breath.
infliximab’s associated debilitating side effects (i.e. psoriasis, shortness of breath, infection, and lymphoma) further threaten a patient’s ability to respond and remain on the drug for an extended period of time. Studies have shown that approximately one third of patients with moderate-to severe Crohn’s disease do not respond to current treatment with TNF inhibitors and another one third of patients only have a temporary response. ¹⁰⁰

*The Clinician’s Cyborgless Understanding of the Patient-drug Entanglement*

A discourse called “drug optimization” has been employed by clinicians to systematically discuss and devise ways to optimize the drug’s efficacy with respect to these two mechanistically driven, unintended drug consequences 1) preventing antibody development (resulting from its foreign materiality) and 2) minimizing and communicating risks of side effects (resulting from its suppression of immune functioning).¹⁰¹ Drug optimization has become a top priority in the clinical management of IBD. Thus, it is an evocative site for illuminating how clinicians view and understand the patient’s relationship and response to the drug exclusively with respect to the body/drug’s biochemical properties and materiality. Importantly, this material conceptualization of the patient-drug relationship drives clinical practice by guiding decisions about drug dosing and selection, driving the development of new objective treatment end goals, and shaping the way practitioners assess and


understand patient perceptions about the drug (through questionnaires).

Consequently, this material conceptualization informs how physicians discuss the drug’s functionality with patients and caregivers as part of shared decision making.

To prevent antibody development, for example, practitioners have historically prescribed immunomodulators (i.e. methotrexate and thiopurines) to be taken concomitantly with infliximab, as these drugs mechanistically interact with both the biologic and with the immune system to prevent antibody formation. In 2010, however, a research study was published which showed that concomitant biologic-immunomodulator therapy increases lymphoma risk almost five-fold. Since then, a new antibody prevention method, called therapeutic drug monitoring (TDM) has gained traction amongst clinicians. Based on the understanding that immunogenicity develops when a patient has low serologic drug levels, researchers developed an assay to monitor infliximab drug and antibody levels within a patient’s blood stream. The assay gives doctors a better understanding of how a patient is metabolizing the drug, which consequently allows them to modify dosage levels to ensure that a patient has enough drug in their system at all times. Infliximab is metabolized differently in all bodies based on medical and demographic variables such as smoking status, being overweight, having high C-reactive protein levels and active inflammation. Thus, while all Infliximab drugs share the same fundamental mechanism of binding to and deactivating TNF, there is substantial interindividual pharmacodynamic variability.

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between patients at a given blood plasma concentration. One patient, for example, may need an infliximab dose of 10mg/kg every 4 weeks, whereas another might require a dose of only 5mg/kg every 8 weeks. In short, TDM technologies exemplify clinicians’ understanding that the patient-human relationship is characterized exclusively by material, molecular metabolism. The clinician’s view of the drug as a discrete material agent allows them to make dosing decisions based on the output produced by their associated surveillance technologies.

A paper by a prominent pharmacologist Arnette Gross entitled “Best practice in therapeutic drug monitoring,” describes the role of the clinician in translating raw drug levels into clinically meaningful information that guides drug decisions:

Therapeutic drug monitoring is a multidisciplinary function. Accurate and clinically meaningful drug concentrations can only be obtained by collaboration between scientists, clinicians, nurses and pharmacists (the TDM team) and excellent communication is necessary to ensure that best practice in TDM is achieved…therapeutic drug measuring is only one part of therapeutic drug monitoring (TDM) which provides expert clinical interpretation as well as the concentration.

This excerpt nicely illuminates the nature of the relationship between practitioner and drug level output—that drug levels are only meaningful if they are gazed upon by the clinician and other members of the team who carry specialized scientific/medical knowledge. Notably, patients are the only actors left out of this system, implying that

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their experience/perception of the drug is not considered meaningful to dose decision making. Physicians only think about the drug-body relationship in terms of material entanglement, as opposed to capturing the greater depth of entanglement allowed by the cyborg. Yet, considering the cyborgian understanding of the non-material nature of this relationship may be crucial in explaining how parts of the patients’ non-material experiences and perceptions of the drug are lost in clinical discourse. This process exacerbates the chasm of understanding and mistrust between doctor and patient.

Not only do physicians view the human-drug relationship solely in terms of materiality, they also importantly perceive the patient’s understanding and concerns of the drug in the same light. This notion is demonstrated by a questionnaire that clinicians commonly give patients to assess their perception of the drug. The questionnaire shown in Figure 2 was screenshots from a publication entitled “Patient’s perspectives important for early tumor-necrosis factor treatment in inflammatory bowel disease,” but notably several other surveys have been developed that execute the same scope of inquiry.  

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This questionnaire notably takes an approach to understanding the patient’s relationship to infliximab that is framed around their perceptions about risks versus expected remissive benefits—two vague biomedical concepts whose discursive meanings vary depending on the cultural, social and etiological knowledge systems of the interpreter (in this case, the patient). The objective of this survey was to develop a better understanding of patient’s pre-conceived perceptions/concerns about the drug, which, often times transcend the “risk-benefit” discussion imposed by practitioners in this survey. Discussions about risks and benefits encompass a discourse that is rooted in a reductionist material conception of the body/drug relationship. It is evocative, then, that no question on this survey inquires about the patient’s beliefs regarding how to define (acceptable) risk and benefits, nor inquires about how culturally prescribed meanings of pharmaceutical drug use might inform a patient’s response to the questions. In short, while these questions certainly point to real, salient concerns of patients, their scope is framed around a limited, cyborgless assumption of how patient’s think about drug use and efficacy. So, then, what aspects of the patient’s
cyborg ontology are physicians failing to address in these questionnaires and in practice?

*The Cyborg Patient’s Lived Experience*

In this section, I examine passages written by real IBD patients as published on a popular online support website called crohnsforum.org. Crohn’s forum provides a digital platform for patients and caregivers to reach out to one another to discuss concerns/questions related to ‘all things IBD’, including experiences with medication, diagnostic procedures, advice about pain/symptom management, psychosocial stress, among other topics. I will showcase a few notable patient blog posts that illuminate a few sources of the doctor-patient chasm as pertaining to differing conceptualizations about infliximab (Remicade). As described earlier, doctors view the entanglement between patient and the drug differently than how patients experience it. The difference in subjective experiences and interpretations about infliximab’s properties partially results from the clinician’s and patient’s disparate beliefs about causation which in turn, lead to differing beliefs about what is the optimal way to treat the disease. Regardless of the accuracy of the patient’s medical/scientific knowledge, the difference in etiological and treatment models between patient and doctor is clearly a source of mistrust between the two parties. With respect to IBD management, the most common competing treatment system to pharmaceutical drug treatment voiced and practiced by patients is “diet.” According to the Crohn’s and Colitis foundation,
diet is one of the most common concerns voiced by IBD patients, and many believe that diet may play a focal role in causing and ultimately curing the disease.  

There are several well-established standardized diets employed for IBD treatment/management. For example, the Specific Carbohydrate Diet (SCD) involves consuming specific carbohydrates that require minimal digestive processes and can be fully absorbed, such that there are none left over to cause intestinal bacterial overgrowth, intestinal irritation and inflammation.  

Another diet intervention system, the elemental diet, involves an even more rigorous regimen of ingesting liquid nutrients that are broken down into their most assimilated, digested form (i.e simple amino acids, fats, sugars, etc), such that the patient’s intestinal system has to exert little mechanical and digestive energy. This latter diet has been employed by patients who have bought into an etiological disease model that opposes the prevailing “autoimmune” model that most clinicians promote. The competing etiology system posits that Crohn’s Disease is, in fact, a bacterial infection caused by the Mycobacterium avium paratuberculosis (MAP) subspecies, a bacteria that is known to cause Johne’s disease. Johne’s disease is a chronic syndrome that manifests in industrial cattle and whose symptoms present similarly to that of Crohn’s.

Despite there being substantial recognition of this alternative etiology and treatment model by scientific researchers and practitioners, this alternative belief system has been refuted by most biomedical clinicians, pharmaceuticals and

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106 “The relationship between food and IBD.” Crohn’s and Colitis Foundation.  
107 “Science behind the diet.” Breaking the Vicious Cycle.  
prominent nonprofits like the Crohn’s and Colitis Foundation. The latter contends that “there is no evidence that anything in your diet history caused or contributed to IBD.” As further stated on the Crohn’s and Colitis Website, most gastroenterologists perpetuate the notion that “while a healthy diet can help you maintain good nutritional status and manage symptoms, medications are recommended to effectively treat IBD.” Essentially, while clinicians do not discourage patients to use diet as a form of symptom management, they ultimately see it as a regimen to be used in tandem with pharmaceutical biologic intervention. Regardless of which etiology model is “true,” it is undeniable that patients’ belief in diet (and its corresponding causational model) substantially informs their perception of the biologic drug. Importantly, this indicates that their entanglement with the drug is influenced by more than that of the body/drug’s material interaction with each other. The influence of diet belief on drug perception was a theme voiced by several patients on crohnsforum.org. One patient, who goes by the username “Fog. D” pointed to diet as a prominent source of conflict and mistrust between him and his doctor. The following was taken from a thread called “I want off remicade!”

“My next infusion is next week, and I REALLY dont want to go! I honestly dont want any drugs in my body anymore! Some of you may think Im being stupid, and you may be right, but I have adopted a "your body does everything for a reason" type attitude and I believe medication only treats the symptoms not the cause! I know my GI isnt going to be happy, in the beginning he told me "diet and food have no affect on Crohn's" and "probiotics are a waste of money!!" I am living proof to the contrary! So I dont really value his opinion!”........I dont by any means think this way is for everyone, I just want

everyone to do some research and educate yourself. Don't do what I did for so long, and stick your head in the sand and put blind faith in your doctor.” — Fog D, 7/12/2011, Thread: “I want off remicade.”

There are several notable themes elicited by Fog D’s post: first, it is evocative that Fog D states that he doesn’t believe that medication is addressing the “cause” of his disease. While he doesn’t explicitly elaborate on what his causational belief system is, it is apparent that diet/probiotics respond better to his model than do biologic medications. Furthermore, Fog D’s reflection that “(he is) living proof to the contrary” alludes to the notion that Fog D’s cyborg entanglement with Infliximab transcends that regarding his body’s material pharmacokinetic properties acting and being acted on by the drug. Rather, his relationship with infliximab is influenced by his total embodiment of a competing etiological belief system, that, similar to an immunogenic reaction, is structurally designed to fight against infliximab’s drug mechanism.

The concept of cyborg encourages us to break down the boundaries that uphold certain social, material and ontological binaries in the world. For example, Haraway specifically describes the cyborg in the context of her urging the breakdown of the border between animal/human, human/machine, and material/non-material; however, the metaphoric cyborg also has been used by scholars to fight for the border-breakdown between dominant and alternative knowledge systems.110 Within the realm of IBD practice, clinicians and patients alike describe diet (and its associated MAP infection model) and biologic drugs (and its corresponding autoimmune model)

as distinct knowledge systems that lend themselves to distinct treatment regimens. However, another cyborgian aspect of the human-drug relationship that was voiced by patients on the Crohn’s forum website was that regarding the blurred boundary between diet and drug efficacy. Below is a blog post written by crohnsforum.org user “Christy87.”

“I have been spending a lot of time at Barnes & Noble and looking online for diets and natural inflamatories that could help so I can eventually get off of Remicade. Brian, I think that's awesome that you have been able to figure out the diet that works for you. I have been trying to figure out mine, but I really haven't noticed any problems with foods besides tomatoes being too acidic and nuts not agreeing with me. It worries me that Remicade has just been masking the symptoms and I am not able to tell the difference.”—Christy 87, 4/5/13, Thread: “I want off remicade.”

That Christy87 is “worried” that she can’t “tell the difference” between the effect of diet and Remicade (infliximab) points to a mindset that is enforced by western biomedicine—specifically the personalized medicine paradigm—which encourages the notion that disease etiology/manifestation is personalized to an individual, and consequently should be treated with one mode of personalized pharmaceutical intervention. However, when looking at Christy87’s experience through the lens of cyborg, the possibility of a blurred boundary between drug and diet efficacy would be well-embraced and encouraged. It seems that Christy87 is experiencing a dissonance within her own body as a result of a cyborgless mentality conflicting with her perceived bodily experience. While I have focused my analysis on Fog. D’s and Christy87’s posts, I would like to note that eight other patients (out of twenty-five) on this thread spoke to diet being a primary source of disagreement with their practitioner in the context of the larger infliximab/biologic discussion. Thus, it is noteworthy that the survey aiming to
assess “patient perceptions” of infliximab failed to address this prominent aspect of the human-drug relationship.

There is one last aspect of the human-infliximab entanglement that I would like to illuminate, regarding a phenomenon I observed in several posts by crohnsforum users. That is, in the context of talking about their opposition to Remicade, several patients described their overall health, wellbeing, and bodily symptoms with respect to the timing of their Infliximab infusion. Below are a few posts from crohnsforum.org exemplifying this phenomenon:

“The other funny thing is I am on a double dose of Remicade every six weeks, and it seems like as I get into that 5 and sixth week my health is at a peak, and then after the infusion its like it declines a little again. I know that is weird and a little backward to how it should be, but that is what I have noticed.” — Fog D, Thread: “I want off remicade.”

“I am fatigued a week before my treatment is due. I feel energized after my treatment....I say it's my 'go-go' juice.” —imisspopcorn, Thread: “Remicade—How do you feel immediately afterwards.”

In the first excerpt, the patient describes a regular occurrence of specific symptoms in relation to the timing of his infusion (“5 and 6th week” → infusion → health decline). The question of whether the infusion, was, in fact, acting materially on the body such that the patient would feel such symptoms is not so much as notable as the notion that the patient seems to have developed a sense of their body that is centered around their drug consumption. In general, patients seem to embody infliximab in intangible ways that cannot quite be captured or predicted by objective drug levels or inflammatory markers (hence Fog D’s observation that “it’s a little backward to how it should be”). The sense of having a substance running through the body intangibly informs the way
that the patients understand their own physical experience, whether it be regarding the onset of ameliorative or painful symptoms.

The Entanglement between Patient and Drug Surveillance Technology

As mentioned earlier, infliximab stands out from other classes of drugs (i.e. immunomodulators, 5-ASAs, etc) due to its ability to initiate full mucosal and histologic healing, in addition to instilling clinical pain/symptom relief. Prior to infliximab’s release, clinicians primarily used clinical relief (as per patient report) and temporary mucosal healing to assess the efficacy of a drug. However, after the biologic drug entered practice, clinicians started defining and assessing treatment goals using a new discourse called “treat to target.” The “treat to target” approach to disease control refers to a clinical model in which disease remission is defined by the attainment of specific objective quantitative and qualitative endpoints (i.e. complete mucosal healing, high albumin proteins, low inflammatory C Reactive protein levels, and normal Calprotectin stool levels), as opposed to using symptom relief (i.e. reduced abdominal pain /bowel movement frequency) as the dominant indicator of drug efficacy. It is imperative to understand that the “treat to target approach” did not exist in clinical practice prior to the release and use of infliximab. Rather, this novel treatment priority model emerged as clinicians observed infliximab’s clinical and microscopic effects in patients over the course of several years, and consequently employed the new rhetoric of “changing the natural history of disease” to describe the transformative properties of the drug. Essentially, infliximab first produced certain observable and measurable outcomes. Next, these endpoints re-oriented the use of
pre-existing disease surveillance technologies (such as colonoscopy imaging) as well as fueled new personalized assessments (i.e. fecal Calprotectin stool test) designed to monitor and assess disease severity/status associated and defined by these objective markers. This temporal relationship between drug and endpoint development is emblematic of a closed-loop biomedical process in which medical objectives become defined by specific markers corresponding to one treatment (and associated etiology) model. In the process however, this insular system negates the possibility that other endpoints are important to examine as proxies for health and well being. What aspect of the patient’s lived bodily experience do objective markers/tests fail to capture?

One focal site in which these surveillance technologies have perpetuated the doctor-patient chasm is with respect to exacerbating disparate conceptions/definitions of quality of life (QOL). Quality of life is a highly subjective concept that has been increasingly re-purposed and standardized by biomedical processes and technologies, including imaging systems used to assess for mucosal healing. That is, IBD practitioners have started to describe and define patient quality of life with respect to the objective endpoint of mucosal healing and “changed natural history.” Below is a statement delivered by Dr. Marla Dubinsky for an interview with a popular medical publication called MD magazine in December 2017:

When we think about overall treatment goals, I think all of us similarly want our patients to have no disability and to have a normal quality of life. That is something we all agree on. The question is, are the treatments that are out there now good enough to actually change the natural history of the disease and also limit disability and improve quality of life? There was a picture on
the front of our Journal of Gastroenterology that showed a before and after shot. We’re not used to seeing before and after shots on a medical journal, but it was that dramatic to say you took someone with deep ulcerations and normalized their mucosa. That, to me, finally has caught on now, because we’re now saying that our therapies need to achieve mucosal healing. Why? Because it will implicate on a drug’s ability to reduce the endpoint, which we all want, patients and physicians, which is disability and quality of life.\footnote{Dubinsky, Marla. “Role of TNF-alpha inhibitors.” MD Magazine. Video. 18 December 2017.}

In the first sentence of her statement, Dr. Dubinsky describes how patients define (good) “quality of life— as a conceptualization based around the absence of disability. For IBD patients, disability generally refers to clinical symptoms of pain and diarrhea that inhibit everyday functioning.\footnote{Dubinsky 2017, “Role of TNF-alpha inhibitors”} Dubinsky remarks on disability minimization as a mutual goal amongst clinicians and patients, and follows this up with her question regarding whether “the treatments out there are now good enough” to meet the new infliximab-produced endpoints described earlier. In doing this, Dubinsky illuminates a fork in the IBD treatment decision making processes—a contentious moment in the “tug of war battle” between clinician and patient in which objective endpoints pull patient and doctor priorities in disparate directions.

In recent years, there has been a surge of recognition amongst IBD practitioners to communicate the importance of mucosal healing to patients. This discussion has become central to the IBD Shared Decision making model, which aims
to facilitate patients’ agreement to start early biologic treatment intervention. The last line of Dubinsky’s statement illustrates how physicians communicate this message within the SDM paradigm—that is, they convince patients to start drug therapy by defining/conflating their objective endpoints with the inherently subjective concept of QOL. Gradually, the clinician’s endpoints of mucosal healing and “changed natural history” inculcate patients to internalize a new system for making sense of and measuring their own QOL. Likewise, the patient’s definition of quality of life (as that of minimal disability) re-shapes meanings of the objective endpoints as understood and re-communicated by clinicians. Discourses of QOL and these precision endgoals co-produce each other within a broader discursive context whereby power structures like Big Pharma influence clinicians to understand the obtainment of mucosal healing (and good QOL) as only made possible through the consumption of (pharmaceutical) drug therapy. What clinicians and pharmaceutical developers fail to recognize, however, is that as health outcomes become more “objective” and “quantifiable,” a patient’s understanding of their body may be disrupted and the doctor-patient chasm may be exacerbated. This disruption of a patient’s symptom embodiment is perpetuated by their cyborg ontology.

Indeed, in addition to being material and socially entangled with the biologic drug, patient’s lived experiences are also informed by the disease surveillance technologies (that measure the endpoints.) Consequently, when a patient’s lived bodily experience and perception of QOL conflicts with their own distant data, this

may disrupt their sense of bodily cohesion, understanding, and disease embodiment.

This conflict between lived experience and distant data may manifest in patients who are not clinically experiencing GI symptoms and pain free with a strong QOL, but whose objective inflammatory markers reflect a different bodily narrative. It also may emerge in patients who clinically feel poorly and that they have a low QOL, but whose quantitative inflammatory markers are “normal.” This latter phenomenon was voiced by a crohnsforum user who goes by the name “Suschex.”

“I am curious what other issues could have caused symptoms in the 50% who had no inflammation. I know they always check my stool for c-diff, bacterial infection, etc. but are there other things that mimic a flare? It is so hard to "feel" as if you know what you are experiencing in your GI tract only to be so wrong once they go in and look around. It is like loosing credibility when it comes to your own body!”-Suschex, 12/2/12, Thread: “Switching Anti-TNF Agents: Evidence Based Results and Clinical Experience.”

That Suschex feels that they are “losing credibility when it comes to (their) own body” saliently demonstrates the sense of internal disconnect and uncertainty that patients may experience as a consequence of their clinicians’ narrow, arguably over-precise view of what constitutes a Crohn’s flare. Another poster on the forum, called “Subduedjoy” pointed to the same chasm that has emerged between objective markers and subjective experience, but notably also illuminated how biologic drugs are centrally positioned within discourse connecting perceived inflammation and pain to quantitative measures:

“If you are worried that you may be having inflammation when you aren't having any symptoms, then you can get tested. You don't need to be on medication to make sure you aren't having inflammation.... almost all doctors know only what they were taught in medical school, which teaches how to diagnose and prescribe medications. It doesn't teach about diet.”-Subduedjoy, 5/25/17, Thread: “I want off remicade.”
In stating that “doctors only know… how to diagnose and prescribe medications,” Subduedjoy echoes the concerns and perceptions of many patients who feel that their clinicians aren’t open to considering treatment options outside the realm of western personalized medical thought. Definitions of remissive disease state and good QOL have become so intertwined with conversations about biologic therapy—hence why Subduedjoy made this PSA to other users on the thread that “you don’t have to be on medication” to get your objective markers checked. This relationship is particularly concerning for the way in which the data output produced by disease monitoring assays/technologies, in tandem with therapeutic drug monitoring data, directly inform how clinicians make decisions about drug selection and dosing.

The Clinician’s View and Employment of Therapeutic Drug Monitoring Technologies

As described earlier, therapeutic drug monitoring (TDM) practices involve a series of assays that measure the amount of biologic drug and Anti-Drug Antibodies (ADA) in a patient’s body at a given time point. Specifically, the assay is performed on venous blood, serum, or plasma that is drawn right before a patient is due to take their next Infliximab infusion/dose. In theory, this is when the drug will be at its lowest level (otherwise known as “trough level”). Historically, physicians treating patients with infliximab secondary loss of response have relied on intuition and individual experience to choose between dose optimization of infliximab or switching to an alternative biologic agent.\textsuperscript{114} However, guided by the understanding that

\textsuperscript{114} Mitchell, Robert A., Constantin Shuster, Neal Shahidi, Cherry Galorport, Mari L. DeMarco, Gregory Rosenfeld, Robert A. Enns, and Brian Bressler. "The utility of infliximab therapeutic drug monitoring among patients with inflammatory bowel
antibody production may reduce drug efficacy, clinicians have turned to TDM drug level data, in tandem with clinical symptoms, objective inflammatory markers and mucosal healing status, to make decisions about drug selection and dosing. Recently, a computer software algorithm has been used as the basis for these decisions. The algorithm synthesizes the data points (of symptoms and objective markers) mentioned above in conjunction with other demographic variables and information about disease history, to produce a recommended plan for how clinicians should proceed with drug dosing and selection.\textsuperscript{115} If a patient’s infliximab level is low and a patient is clinically symptomatic, the doctor will most likely increase the dose of the infusion or reduce the time in between infusions. On the other hand, if a patient’s drug level is high but a patient is still symptomatic, the clinician will perform other biomarker tests in order to find other sources of active inflammation. If active inflammation is observed (through colonoscopy, fecal calprotectin, or other biomarker tests), than a doctor may switch the patient off Infliximab, and onto another biologic drug mechanism, as it would indicate that the patient is not response to the anti-TNF mechanism of the drug.

Figure 3 demonstrates the drug decision making process that clinicians follow, that is prescribed by the TDM software algorithms:

\textsuperscript{115} The other demographic variables and information about disease history include disease location and disease classification (characterized by the presence of complications (i.e. abscess, obstruction,) and extraintestinal manifestations.
Given the dominant role that TDM algorithms play in the drug decision making process, it is important to understand the knowledge system and bodily assumptions that the technology uses to make meaningful decisions for patients. TDM technologies are grounded in a cyborgless way of viewing the human-Infliximab relationship. That is, therapeutic drug monitoring practices operate under two assumptions: first, it assumes that there is a definable relationship between drug dose and blood drug concentration; second, it assumes that there is a direct correlation between blood drug concentration, pharmacodynamics and clinical effects.\textsuperscript{117} This latter assumption is inherently grounded in a cyborgless, biomedical framework of understanding the body, in the way it assumes that the drug is acting on the body in a discrete, predictable and material manner such that an algorithm can capture the totality of the drug-human entanglement. The notion of treating cyborg bodies based

\textsuperscript{116} Mitchell et al 2016, “The utility of infliximab”
\textsuperscript{117} Gross 1998, “Best Practice in Therapeutic Drug monitoring.”
on data output from a surveillance system (and interpreting clinician) that fails to view their ontology as such, might serve as one source of disconnection between patient and practitioner when discussing treatment options. The process for developing the target therapeutic concentration range for a given drug serves as another potential source of disconnection between patient experience/perception of symptoms and distant TDM data. According to Mitchell et al, “the therapeutic ranges are established during prospective studies of clinical outcome in a relatively small number of patients and these ranges may differ between laboratories.”¹¹⁸ These variations may result from differences in the way local clinicians view the appropriate target range (based on individual experience and varied published reports), as well as from different indications for populations with age or ethnic differences with differing pharmacodynamics profiles.¹¹⁹ Still, despite these sources of variability, TDM data is considered to be an “objective” decision making tool for IBD patients and particularly for patients with secondary loss of response.¹²⁰

A closer look at patients’ experiences, however, indicate that the data produced by the TDM surveillance technologies are not nearly as “objective” as clinicians may believe them to be. In actuality, humans have cyborgian relationships with TDM distant drug level data such that, in some cases, they start to frame/experience disease symptoms within the context of their “objective” drug levels.

The Entanglement between Patients and Therapeutic Drug Monitoring Output

The human’s subjective experience and interpretation of their bodily symptoms (the patient’s gaze) are highly entangled with the quantitative drug levels (the technical output) produced by the therapeutic drug monitoring surveillance system. This phenomenon was voiced by a few patients on crohnsforum.org including a Crohn’s patient who goes by the username “Rygon.”

“I had my levels checked the other week as I seem to be feeling less well on remicade. My antibodies were <10 and my remicade levels were 2.4 at the time of my next infusion (<2 is supposed to be too low). So it seems I should be feeling better than I am-- The GI did say that they are finding this common and have changed my infusion times from 8weeks to 6weeks to see how it goes. They are now taking blood tests for checking the antibodies and levels before every infusion now”—Rygon, 5/15/2013 Thread: “Developing remicade antiboies?”

The fact that Rygon had his levels checked in response to his poor subjective affect illuminates the biomedical system/clinician’s assumption that there is a likely correlation between symptoms and objective drug levels. During clinical interactions, the patient internalizes this notion that subjective experience can and should be reflected by technical output—hence why Rygon voices that “he should be feeling better than (he is).” Rygon’s confusion regarding the discrepancy between the bodily narrative represented by his distant data versus that of his own sensory perception, demonstrates how the technician’s gaze is entangled with Rygon’s own way of gazing into his body. Importantly, in this scenario, the patient’s subjective experience was used to inform the subsequent treatment plan despite the fact that his data was “objectively” in the normal range. The fact that the only clinical modification that was made was to the treatment regimen, reflects the clinician’s lack of consideration of other factors that may have contributed to his subjective complaints.
Another patient, “Keenie,” further demonstrated the way in which TDM output informs a patient’s interpretation of their own bodies.

“I’ve just had my 10th infusion. I go every 8 weeks. I have excruciating migrating joint pain at about 6 weeks post infusion. It’s happened only on the last 2 infusions. maybe I need to get them 6 weekly. the pain is killing me. I know the remicade has done this to me. Nevr evrr had joint pain prior to remi.”—Keenie, 2/17/14, Thread: Developing remicade antibodies?”

While Keenie does not explicitly mention his numerical drug levels, the fact that he voices that he may need infliximab (Remicade) infusions every 6 weeks—in temporal alignment with when his pain is exacerbated—implicitly reflects that he is understanding his symptoms as a result of his needing a higher drug dose. In short, Keenie is understanding his own embodiment through the technical representation system of the therapeutic drug monitoring technology.

The final empirical evidence I provide for the entanglement between patient and TDM output, comes from my professional experience working as a clinical research coordinator at a prominent IBD tertiary treatment center in New York, New York. For two summers, I conducted research examining the clinical and histological efficacy of performing TDM blood assays at various time points after starting infliximab therapy. Furthermore, I attended weekly case conferences, journal clubs and pathology sessions, as well as shadowed clinicians at the center during their patient consultation sessions. Through these experiences, I developed a tremendous amount of tacit knowledge regarding the process by which clinicians understand patient disease embodiment and make treatment decisions. In attending patient sessions, I also gained firsthand insight into how patients interpret information regarding their disease diagnosis, treatment options, and objective disease and drug
markers, including TDM levels. While I did not officially interview patients regarding their perceptions and experience with therapeutic drug monitoring practices, I would like to briefly share the lived experiences that several patients voiced during the sessions I attended, regarding their interpretation of objective drug levels.

First, there were several patients, who, right before they were due to get their next infusion (theoretically when their drug level was lowest), voiced feeling a sense of fatigue and/or vulnerability within their intestinal tracts. One patient explicitly voiced concern that their “drug level was low” and asked the physician to get their drug levels tested. The notion that the patient, themselves, turned to their distant drug levels as a primary explanation of symptoms is reflective of a significant adaptation process that patients undergo as they learn to describe and make sense of their symptomatology with respect to their distant drug data—and more broadly to the knowledge/meaning systems enforced by the biomedical complex. In this case, the patient demonstrated their cyborg entanglement with both the material drug and the drug surveillance system. Another interesting phenomenon voiced by a patient was regarding the way that knowledge of their quantitative drug levels directly influenced their physical experience of symptoms. One patient, who historically suffered from joint inflammation (in addition to intestinal symptoms) described feeling an acute sense of pain in their ankle whenever their drug level was lower than what the accepted target range dictated. However, when their drug levels were in the normal range, their subjectively perceived sense of inflammation was much lower than in the former scenario. Importantly, the discrepancy in this patient’s subjective experience
of pain/inflammation was not correlated with a substantial difference in objective inflammatory markers indicating active disease (i.e. C reactive protein, sed rate, etc). In this case, self-knowledge, a non-material actor, engaged with the patient’s bodily materiality, and consequently informed clinical practice.

The Future of Shared Decision Making in IBD Practice

Throughout this chapter, I have described the central roles that biologic drugs, “objective” disease endpoints, and disease/drug surveillance technologies play within Shared Decision Making practices. In sum, the “treat to target” approach to disease management serves as the backbone of current shared decision making practices. The treat-to-target approach is not just boasted for the way it has improved patient clinical outcomes. It is also universally promoted for the way it improves clinician-patient modes of communication and general interactions. Dr. David Rubin, a prominent expert in IBD, proposes that “the treat-to-target approach of objective targets of disease control and serial adjustments to therapies can strengthen the doctor patient relationship in IBD by enabling defined trials of alternative approaches, followed by a more objective assessment and reconsideration of treatments.”¹²¹ This statement is emblematic of the larger mission statement of SDM that promotes a platform for patients and physicians to equally contribute to the treatment decision process.

However, a closer examination of IBD SDM approaches as presented in other clinical

gastroenterologists’ publications/testimonies indicates that Dr. Rubin’s statement, while well-intentioned, is not quite actualized in practice.

The reality of Shared Decision Making in IBD practice is that it is grounded in the over-arching goal of clinicians to start patients on biological therapy as soon as possible after their diagnosis. Conversations between patient/caregiver and doctor about biologic therapy is centered around the biomedical concept of risk. In the case of IBD, risk is discussed with respect to risk of immunogenicity (antibody development) and risk of developing complications. The future of IBD management and decision making will not just focus on patients starting biologics (as a broad class). Rather, SDM technologies will be used to identify/assess certain demographic, biological and genetic factors in patients to consequently stratify them into their personalized, optimized biologic treatment group. A validated online report about (future) SDM tools elaborates on the goals of these technologies in IBD practice:

An individualized, web-based tool for patients and clinicians attempts to bridge this gap (of knowledge of who will respond to therapy) by predicting an individual patient’s risk of complications. The prediction model incorporates age; sex; disease duration, location, and phenotype; dates of disease complications and medication exposure; serologic immune responses; and NOD2 genotype status. After the prediction model was validated in external pediatric and adult patient cohorts, a patient-facing web-based tool was developed. This tool, which displays the 3-year individualized probability of complication development (Your Crohn’s Disease) and summarizes the benefits and risks of treatment options (Your Treatment Options), facilitates
shared decision-making. Pilot testing with clinicians and patients found excellent comprehension.\textsuperscript{122}

As demonstrated by this passage, the improved SDM-technology mediated doctor-patient relationship that Dr. Rubin boasted about, in fact, refers to the greater ability for clinicians to communicate the risk and complications that a patient will experience if they do not pursue early biologic therapy. It is implicitly made clear that the “excellent comprehension” established by pilot testing of this program reflects the greater comprehension and acceptance patients had of their clinicians—not the other way around. This one-way communication/education feature of the technology represents one feature of a broader physician-patient power gradient perpetuated by the SDM paradigm.

Another way that the SDM driven power dynamic manifests concerns the notion that this online-tool encourages a conceptualization of risk, complications, and embodiment based around genetic markers (i.e. Nod2 genotype status). Clarke et al 2010 argue that the increased conceptualization of health, disease, and human ontology with respect to technoscientifically produced data output and genomic markers exemplifies a central process of biomedicalization: the transformations of bodies to include new properties and the production of new individual and collective technoscientific identities. In general, western gastroenterologists view the SDM model and its associated technologies to be at best, positive, and at worse, neutral mediators of bodily truth and clinical relationships. What they fail to acknowledge, is

the bodily and social transformations that patients undergo as they adapt conceptualizations of their disease that are based around the language and representation systems of their clinicians.
**Conclusion**

The proliferation of biotechnologies into medical practice has transformed the way the physical body has been defined and surveilled, how disease has been conceptualized and treated, and how the power gradient between clinician and patient manifests. These biotechnologies, namely including drug therapies, diagnostic technologies, drug surveillance tools, and communication technologies, have produced new forms of scientific and clinical knowledge that promotes numeric, technical biomarkers as the gold standard for capturing “objective” narratives of pathology, health, and risk. Importantly, these biomarkers have become the language of a new bodily representation system used by clinicians to signify states of health, disease, and quality of life. This representation system is grounded in the assumption that the patient’s body is a discrete, neutral material agent such that its functioning can be comprehensively surveilled by assessing its material biologic markers. Similarly, the representation system views biotechnologies as material, technical entities that instill or surveil bodily function but whose ontologies are ultimately separate from the human.

The reality, however, is that bodies and biotechnologies are both highly discursive agents whose meanings, ontologies and relationalities are far more complex than what are acknowledged by clinicians and scientists. The cyborg framework allows us to understand humans and biotechnologies as being inextricably entangled with each other. Human bodies are best understood as a highly dynamic interplay between human physiology, mechanical circuitry, cultural and technical discourses, practices, ideas and material objects. Furthermore, the human’s subjective
experience and interpretation of their bodily functions (the patient gaze) are highly intertwined with the technical output that are used by clinicians and technicians as the basis for treatment decision making. The inability of clinicians and the broader biomedical system to see the complexity of these dynamics has exacerbated the power imbalance embedded in the doctor-patient relationship, specifically in the context of treatment decision making discussions. Furthermore, the clinician’s understanding of the patient as merely a material system of genetics and biology has minimized patient agency and perpetuated communication barriers both within a body and between patients, physicians, technological representation systems and bodily truth.

In chapter 2, I illuminated how these power dynamics and communication problems unfold between clinicians and patients with Inflammatory Bowel Disease (IBD). The IBD cyborg patient is entangled with two different biotechnologies: first, the biologic drug; and second, its associated therapeutic drug monitoring (TDM) surveillance system. Each of these biotechnologies has produced objective biological or technical data endpoints—produced around the biomedical construct of risk—that are used by clinicians to assess and treat disease, and to guide treatment decision discussions. The chasm between doctors and IBD patients is perpetuated by the fact that each party gazes at the endpoints in competing ways, and consequently struggle to effectively communicate their respective perspective with each other. Shared decision making tools have been introduced as a bi-directional translator to help each party communicate their values and priorities to reach a mutual decision. However, while the decision-making may be shared in theory, it is based on the technical
representation systems—the language—provided by the clinician who holds the expert knowledge. This representation system is incapable of translating lived experiences that are not centered around the biotechnical materiality of the human. The system is structurally unequipped to capture the totality of the cyborg’s ontology and disease embodiment. What key components of the cyborg patient’s experience have been lost in translation?

First, the clinicians do not take into account the extent to which a patient’s sensory experiences and interpretation of bodily symptoms are entangled with the drug and its associated data output. As the materiality of the drug fuses with that of the human, the human may frame their sensations of pain, energy, or fatigue around the timing of their drug infusion. Their physical disease embodiment is also entangled with the objective endpoints used for disease surveillance (i.e. mucosal healing, inflammatory biomarkers) and drug surveillance (i.e. quantitative drug levels) such that knowledge of these markers may perpetuate an internal sense of disconnect and anxiety when the objective markers do not reflect what the patient is subjectively feeling.

While the human-drug relationship certainly involves a material, molecular interplay, there are several non-material, discursive aspects of the cyborg’s embodiment and subjective experience that need to be addressed by clinicians in decision making conversations. The IBD cyborg’s phenomenology should be understood as a combination of symptoms, their interpretation of biotechnical data, their etiological belief system, and medical and cultural discourses, all which synergistically interact with each other to inform one’s response to and concerns
about treatment. Importantly, the biomedical discourse of quality of life informs and often conflicts with that as defined and experienced by patients. For example, many patients define quality of life to be the absence of debilitating symptoms. Their outlook on their life, identity and their disease maintenance regimen may transform as they internalize the biomedical system’s operationalized definition of health and happiness.

Understanding the communication barriers within a body and between doctor and patient as problems of translation lend itself to specific solutions. Haraway contends:

One should expect control strategies to concentrate on boundary conditions and interfaces, on rates of flow across boundaries—and not on the integrity of natural objects. Integrity or sincerity of the Western self gives way to decision procedures and expert systems.\textsuperscript{123}

This excerpt underscores the importance of improving professional-patient communication methods in order to ameliorate health outcomes and minimize the power gradient. One implication of focusing on boundary conditions between the expert physician and layperson is by rethinking how technology should be positioned between physician and patient. Klugman views physicians as “bridges” between humans and machines” that have to “grapple with the question of how much to disclose to patients. They control all forms of intermediary communication about machine function and disease knowledge.”\textsuperscript{124} Under Klugman’s relational model,

\textsuperscript{123} Haraway 2000, p. 302
\textsuperscript{124} Klugman 2001
technological knowledge is conceptualized as an entity to be bridged to the patient (via the physician). Similarly, Bradley Lewis notes that “in this (technoscientific) environment, clinicians are in danger of becoming glorified distributors of the new technologies for the giant transnational biotech corporations—sort of like new car dealers with a medical certificate.” Situating the physician between technology and patient upholds the inherent power imbalance embedded in the biomedical system because this configuration does not allow the patient’s subjective experience to be involved in the interpretation of data and decision making. Thus, cyborg ‘control strategies’ might best be employed under a model that views technology as the bridge between clinician and patient. This distinction provides a framework that acknowledges and embraces the material and non-material entanglement that patients have with their respective biotechnologies. Strengthening ‘the bridges’ between technological hardware usability and software design, clinical practice, patient values, and bodily truth may involve the development of a new, common intermediary language/representation system—one that is not exclusively centered around the linguistics of technology and quantitative programming, and values the importance of the subjective narratives—but that is also grounded in scientific epistemology and methodology.

Finally, by stating that control (treatment) strategies should focus on “boundary conditions and interfaces, and not on the integrity of natural objects”, Haraway implores us to embrace the dissolvement of the boundary between

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“physician” and “patient” in this new digital age. Dissolving this boundary is one way to resist subordination to decision procedures and “expert systems.” More broadly, accepting and integrating other dissolved boundaries into our identities—including the border between material/non-material, culture/nature, dominant/alternative knowledge systems, health/disease—can be part of our empowerment in responding to oppressive institutions that insist on maintaining dualisms in which they dominate. As Haraway states, “the machine is not an it to be animated, worshipped and dominated. The machine is us, our processes, an aspect of our embodiment. We can be responsible for machines; they do not dominate or threaten us. We are responsible for boundaries; we are they.”126 Going forward, I hope we can use the insights evoked by the cyborg to design treatment systems whereby biotechnologies are embraced as permeable portals for communicating knowledge, reflecting bodily truth, and dissolving boundaries—not creating them.

126 Haraway 2000, p. 315
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