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“They’re Still Trying to Wrap Their Head Around Forever”: An Anatomy of Hope for Spinal Cord Injury Patients

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“They’re Still Trying to Wrap Their Head Around Forever”:

An Anatomy of Hope for Spinal Cord Injury Patients.

by

William A. Lucas

A dissertation submitted in partial fulfillment
of the requirements for the degree of
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DEDICATION

To my family, who has allowed me to process and understand tragedy in ways I never could have imagined. I love you.

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To all the participants who allowed me into their lives, peering into their most vulnerable and tragic experiences, thank you. None of this would be possible without your willingness to open up to me, sharing your lives, heartaches, and hopes for the future. Given that this dissertation is all about hope, this publication would never have been possible if not for your willingness to give me this gift. The process of this research was emotionally arduous, and I can't fully articulate how grateful I am for that experience. Without it, this wouldn't be a fully human endeavor.

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TABLE OF CONTENTS

List of Tables	iii
List of Figures	iv
List of Abbreviations	v
Abstract	vi
Introduction.....	1
Chapter One: Disability Anthropology.....	8
Experience-near Approaches in Disability and Chronicity	11
Socio-political Structures of Disability.....	14
The Social Model of Disability: Rehabilitation and Return to Work	17
Anthropology of Caregiving and Social Support.....	20
Science and Technology Studies of Disability	21
Temporality and Spinal Cord Injury	24
Overview and Critiques of SCI Institutions in the US.....	26
Chapter Two: Theorizing Affect and Governmentality in SCI Rehabilitation experience	30
The Deleuzian/Foucauldian “Method”	31
Primary Affects and Secondary Rationalizations	35
The Role of Moral Anthropology	40
Power, Politics, and Identity: Intersectionality	44
The Three-Level Approach: A Brief Example	48
Chapter Three: Research Methods.....	51
Research Site Background	51
Positionality	53
Basic SCI Terminology and Etiology.....	55
Methodological Inclusion in Ableist Anthropology	59
Overview of Methods	63
Sampling and Recruitment.....	64
PwSCI Participants	65
Methods.....	68
Participant Observation.....	68
Epidemiological Survey.....	69
Experience-near Methods	69
Semi-structured Interviews	71

Data Analysis	71
Limitations	72
Chapter Four: The Moral Economy of SCI Care.....	74
How Therapeutic Encounters Lead to New SCI Constructs.....	75
The Case of Tom: Inherent Limitations and Double Binds.....	77
The Case of Jessica: SCI as Transcendent.....	82
The Case of David: Motivation as Differentially Supported.....	84
The Case of Matt: Structural Justifications of Moral Deservingness	86
Analyzing These Cases: KP as Moral Laboratory.....	88
The Moral Imperatives of SCI Rehabilitation at KP	91
Discussion.....	96
Chapter Five: The Structures Driving SCI Rehabilitation Logics at KP	99
Regimes of Truth: How Insurance Logics Organize Therapy at KP	100
Jamie: A Veteran Enabled Hope.....	100
The Governmentality of Insurance Structure at KP.....	103
Regimes of Care: How Medicare Structures What Exists at KP	104
Regimes of Care: How Billing at KP Structures Care.....	107
Structural Anthropology: The Moral Project of Living with SCI.....	115
Maintaining The Active Stance	117
Discussion.....	126
Chapter Six: Ethical Affects: Or, Learning How to Become Paralyzed.....	128
How to Live the Good Life.....	129
Transcendence as Means of Being Affected.....	140
Joking as Affect: Revitalizing and Re/acting to Debilitation	147
Motivation and Hope as a Biocultural Process Towards Healing	150
Bare Repetitions at KP.....	155
Discussion.....	161
Chapter Seven: Discussions.....	163
The Three Level Approach, Redux.....	166
The Phenomenon of Hope	172
The Social/Moral Rationale of Hope	175
Exploring the Structure (and Physiology) of Hope: Evaluating Hope as Biocultural	177
Recommendation 6: Conceptualizing and Measuring Hope	181
Discussion.....	183
Conclusion	185
References.....	197
Appendix A: IRB Approval Letter	219

List of Tables

Table 1:	Summary List of Participant Types	65
Table 2:	PwSCI Participant Demographics.....	66
Table 3:	Breakdown of Steven’s Sessions	111

List of Figures

Figure 1:	Three Level Framework.....	36
Figure 2:	Interactive Three Level Framework.....	37
Figure 3:	Spinal Cord with Associated Functions.....	57

List of Abbreviations

SCI	– Spinal Cord Injury
TBI	– Traumatic Brain Injury
pwSCI	– people/person with spinal cord injury
ABT	– activity-based therapy
KP	– Keep Performing
C#	– Cervical Vertebrae numbers 1 through 8
T#	– Thoracic Vertebrae numbers 1 through 12
L#	– Lumbar Vertebrae numbers 1 through 5
S#	– Sacral Vertebrae numbers 1 through 3
ASIA	– American Spinal Injury Association Impairment Scale

ABSTRACT

This dissertation draws on ethnographic data to investigate the nature of spinal cord injury (SCI) rehabilitation in Central Florida, using participant observation and interview data to understand how people with SCI (pwSCI) conceptualize their own disabilities after experiencing such radical alterations in their subjectivities. Using case studies and ethnographic vignettes, it argues that the extreme double binds in which pwSCI find themselves (where they are personally ordinarily disabled and socially extraordinarily novel; and where they are enabled resources to pursue “hopeful” therapy modalities while being designated as hopelessly disabled) is further polarized by the various legislative regimes of truth in which pwSCI rehabilitation participants find themselves – these include insurance logics, the therapy philosophy of the Dardzinski Method upon which this novel therapeutic methodology (activity-based therapy) is founded, and the various internal and culturally-supported standards that present themselves through various dichotomous categories.

This dissertation illustrates how these structural systems enable the various moral and emotional normativities present at this rehabilitation center – which I refer to throughout this dissertation as Keep Performing (KP). This dissertation also presents routes through which normative affects (i.e., ways that pwSCI are in/capable of being affected at KP) are both reinforced through motivational therapeutic processes (i.e., instances of joking) and challenged through daily experiences (e.g., where pwSCI are given opportunities to reorient themselves vis-à-vis their own subject positions and that of other pwSCIs). I conclude that activity-based

therapy constitutes a novel therapeutic modality where pwSCI are enabled ways of reorienting themselves contra normative therapy modalities, carving a space for hypothesizing how *hope* can be useful both pragmatically/therapeutically and theoretically/philosophically.

Introduction

This project originated from a deeply personal, familial experience involving sociohistorical, interpersonal relational, and subjective emotional dimensions of human life. Which is an anthropological way of saying, shit happens for reasons, and sometimes shit hurts. In 2007, my brother Michael was involved in a drive-by that occurred around 11PM on August 14. He had been visiting with a friend and his parents, celebrating this friend's birthday. The two shots in his neck affected his spinal cord at the cervical 1 and 2 levels, rendering him a quadriplegic. For the next several years, I became one of his primary caretakers, helping with his many daily activities, functions, and responsibilities.

From the time I made the decision to pursue anthropology (formally/bureaucratically in 2010), I evaded anthropologizing this situation. Yes, studies like that depicted in Lawrence Ralph's 2014 *Renegade Dreams* could contextualize how community divestment alongside a concurrent proliferation of unregistered firearms could result in violence-induced disability within communities of color. Growing up in Compton, CA lends itself to such correlations and sympathetic reactions from readers merely upon its mention. So, for a time, I pursued other anthropological foci that took me to Guatemala for my master's thesis on processed food proliferation and nutrition in a Q'eqchi' Maya community. However, my family's experiences always plagued my mind.

Arthur Kleinman's 1988 *The Illness Narratives* helped to describe the complicatedness of my brother's ongoing chronic condition. Indeed, chronicity is an intersubjectively constructed phenomenon that involves chronic sufferers, their families, and society at large. Thus,

Kleinman's explanation of how chronic disease sufferers reside within a Batesonian double bind where their families co-construct an illness drama resonated with me. There, the ill are told to be active in their own care, but to also submit to care in order to then be blamed for what they must have done to exacerbate their condition. Everyone – my brother, my family and myself, physicians, and the rest of society – was implicated.

We tend to believe that anthropological research is about understanding life. About narrating and deconstructing situations in order to extract some piece of generalizable tidbit from them. Indeed, Ralph (2014) contextualizes life in the macro, while Kleinman (1988) contextualizes it in the micro. These analyses are astute and deserve to inhabit their places in anthropological work and theory. They help explain what happened and how they intersect with everyday life. Yet, there is little solace in one's situation being describable or depictable. There is even less satisfaction in reading what Geertz (1973, 18) calls "impeccable depictions." We don't do anthropology to generalize, but to uncover and interpret. Perhaps ethnographers share more overlap with journalists than we usually entertain. I'd like to say that this dissertation extracts and interprets truth; with truth being highly situated and provisional: it may have disappeared as quickly as I uncovered it. More on this in a second.

It took reaching the beginning of 2020, during the start of the COVID-19 pandemic, for me to consider seriously tackling spinal cord injury (SCI) as a research topic. And so, after Googling "spinal cord injury rehabilitation," I found a nonprofit center that was close enough and active enough to visit. On February 24, 2020, I visited the SCI rehabilitation center that I will refer to throughout this dissertation as Keep Performing, or KP. Upon this first visit, I met KP's Operations Manager, Katie; the person who would become the Floor Manager during my time doing research there, Daniel; Jack, another one of the several rehabilitation staff members

that I would regularly interface with on KP's therapy floor; and Randy, KP's founder who is a veteran with a C3 level injury which makes him one of the people with the highest level injuries to receive rehabilitation at KP. During my first visit, they all told me about activity-based therapy (ABT) and how KP was dedicated to providing therapies for clients and patients whose lives have drastically changed as a result of their SCI. The long 2-hour sessions that characterize KP rehabilitation is practiced at few centers, and they told me that the benefits were substantial. There was so much there that I was sold.

It would be another year and a half, on September 29, 2021, when I would formally start data collection at KP: after finishing coursework, submitting several unsuccessful grant proposals, and completing my IRB paperwork. This dissertation is based on 10 months of data collection where I built connections with rehabilitation staff and several people with SCI (pwSCI) with whom I still regularly communicate.

Going back to the point I started with above, I wonder, by doing this research, did I ever actually *engage* with my family's situation? Is it correct to assume that since I did research with pwSCI, then I clearly confronted something intrinsic about my brother's injury, his situation, his subjectivity, and in some measure, my own? I don't think so. And I think that's the point of this whole dissertation. If we predicate difference on conceptual links, then are we ever really engaging with what really matters? Concepts like intersectionality question this inclination to generalize, arguing that even those who inhabit the same exact identity categories often have vastly different experiences. Of course, they do. As philosophical as these considerations seem, anthropology is most adept at engaging them.

The theories I use throughout this dissertation interrogate the practice of uniformity – when we create a concrete object with which to study, test, hypothesize about, and about which

to make grand conclusions. It is easy to generalize SCI as a condition in which individuals are thrust; where engagement with parts of one's body is cut off; or where one might be rendered disabled and abandoned by society's norms. Thus, I could easily conceptualize an interlocutor's anger, situating it within this zone of abandonment. Perhaps activity-based therapy could be situated as an act of resistance. However, in writing this dissertation, I realize that what matters is being in relation. Activity-based therapy's status as a non-normative, even deviant, form of rehabilitation need not arise from some grand claim about tyrannical power relations and anti-authoritarian resistances. As I elaborate later, I find Graeber's definition of consensus much more useful, where consensus is "coming up with a creative solution that nobody violently objects to" where "consensus does not mean unanimity" (Graeber 2013a). Thus, consensus exists on account of its being hegemonic and implicit, and rarely explicitly contested.

The real people I encountered during my research inhabit this more modest cultural field: where most medical professionals generally want the best (and will even advocate) for their paralyzed patients, but are nevertheless constricted by institutional logics, bureaucratic routes of transformation, and normative social stances (created by both medical training and U.S. culture); and where exclusion stems from what might be termed temporally magnified inconveniences. For instance, few overtly wish that wheelchair users stay home, but many public spaces in Florida, such as sidewalks, tabletop heights in restaurants, and building entrances nonetheless make inhabiting the outside world a trying space to navigate. PwSCI often need assistance and find themselves waiting until it becomes available.

Thus, rather than relegating "reality" to anthropological "impeccable depictions," this dissertation interrogates various norms such as analytic norms (e.g., to inductively create broad categories of difference), social norms (e.g., about the kinds of barriers and affordances our

spaces infer), psychological norms (e.g., about the kinds of lives worth living), and bureaucratic norms (e.g., the kinds of activities and therapies deemed appropriate for SCI patients to practice). Most importantly, this dissertation is interested in how these norms are challenged and often upended during the process of engaging in activity-based therapy at Keep Performing.

How do these norms remain so pervasive and enduring? This dissertation is also about how the stories we tell one another are only “logical” under certain, invoking Foucault (2008, 18), “regimes of truth.” The truth uncovered here is provisional, yes, but the sociality in which it is embedded persists. As does the process of coming to terms with one’s injury described here. This dissertation centers a “three level” model/approach to apprehending these data. And much of what I mean by this is written in this introduction. Our impeccable depictions can fall short because they’re narrative fantasies. They can be helpful for appreciating another’s situation. And ethnography is one such example. But we hope they can at least be useful.

In Chapters 4 and 5, I outline the utility of such narrative fantasies and the kinds of worlds they help create. In Chapter 4, these are described through the various case studies presented. The statements that people utter are situated. I center the stories of veterans and civilians who are and are not covered by insurance, and one whose history of drug use has led to repeated situations where he has been ignored and thus harmed in the process. This helps flesh out the morality with which activity-based therapy at Keep Performing is infused: it is a space where patients and clients can be seen, heard, and engaged. In Chapter 5, I describe in what they are situated – such as bureaucratic structures as well as the binary oppositional narratives that compel KP staff and rehab participants to depict their own situation in these moral terms. Much of this dissertation is about sorting through the morality to find the ethics. In other words, sorting through the value-laden judgments to uncover the normative structures hidden underneath. These

are my secondary and primary levels of analyses, respectively. I connect norms and judgments by situating norms as inherent to our cultural development, and evaluative judgments as how we translate that to ours and others' lives. Things like the binary oppositions that structure these secondary utterances make up my tertiary (political) level. Indeed, we have to get from norms to judgments somehow; and in this dissertation, structures like Medicare, physical therapists' training, and medical knowledge about SCI each contribute to naturalizing the kinds of recommendations and prescriptions given to SCI patients and clients at Keep Performing. My three-level approach is fully outlined in Chapter 2, with all the proper, necessary citations.

Moving on to the primary level: the use of narratives is, I argue, in the gaps. Disability scholarship critiques normative ableism. Yet, what is normal is perhaps the most logical as it is historically created while also being socially empowered. Social consensus is necessary, but also not so hard to come by. The primary level entails this set of normalization processes. These are fleshed out most in Chapters 6 and 7. In Chapter 6, the structural origins of hope and how it exists in clinical space are examined. Through phenomena such as joking, collaborative therapeutic encounters at Keep Performing are also situated as ways of creating informed instances of acceptance, where pwSCI come to view their SCIs as enduring yet immanently in flux. In Chapter 7, I describe the open-ended nature of hope, and how all three levels come to bear on this seemingly singular concept that is anything but. Describing instances of transition, where SCI participants transition from outcome to process oriented ontologies of hope, I suggest some concrete directions for how to interrogate hope clinically. I also offer some suggestions for how we might improve rehabilitation options for pwSCI.

By describing the various interactions that occurred during my time at KP, I hope to contextualize the difference between the said and the done. Including how the said and the done

tended to change over time, such as the instance when Jessica, a patient at KP, told me at the tail end of my time there that she accepted that she would likely never walk again. This is noteworthy as Jessica was also the first to guide me on a path of how physicians can often be wrong in their prognoses – indeed, she learned how to use a manual wheelchair and how to transfer herself to and from her chair on her own through therapy at Keep Performing. Rather than this transition being optimistic or pessimistic, such case studies illustrate three-level transformations where SCI participants feel, think, speak, and move differently in the world. These are ontological and far from modest differences, despite their seemingly modest shifts. Similarly, distinguishing between the acceptance of physicians and that of KP’s rehabilitation staff makes all the difference for Jessica’s ability to move forward in life and rehab. These, too, are felt differently and in fact inhabit different emotional and affective spheres – one in a strict moral binary, the other in an ethical temporality.

The stories and analyses within this dissertation attempt to see beyond the words used, defining them as laden with baggage. If we look beyond our words, what would we find? By the end of reading this manuscript, I hope you’ll see that I found a space for hope that is clinical, narrative, and affective. In other words, “hope” is therapeutically relevant (clinical); the glue that depicts an emotional world (narrative); and a concept that can be further illuminated by understanding the temporally contrived normative subjectivities that it depicts (affective). This biocultural approach to hope carves out a space for how narrative and structure are embodied. And by placing structure, power, and affect alongside one another, I hope that the conclusions I reach in this dissertation are less about finding satisfaction, and more about apprehending humanity in its fullness – which is inherently and irrevocably unfinished.

Chapter One: Disability Anthropology

A focus on disability in anthropology arose out of developments within medical anthropology in the 1980s and 1990s, which helped create new frameworks to operationalize illness, chronic disease states, and other complex phenomena and systems that anthropologists were encountering in the field. A focus on disability is now understood to have come about through three perspectives that brought about disciplinary shifts and tensions within medical anthropology—these overlap, and while it can be difficult to distinguish between them, they also contextualize how disability is currently conceptualized and theoretically articulated in medical anthropology.

These three perspectives are drawn from (1) Marxian critical theory as proposed by Eric Wolf (1972), which highlights bodily embeddedness in the capitalist world system; (2) postmodern skepticism, which questions the modern project guiding Western biomedicine separating disease from social and cultural processes (Scheper-Hughes and Lock 1987); and (3) phenomenologically-oriented, experience-near approaches that centralize ethnographic descriptions and narratives in order to situate illness, suffering, disease, and stigma with respect to the sociocultural processes in which they are embedded (Biehl 2013; Kleinman 1988; Good 1993). The implications derived from these conceptually distinct fields being entangled are that it collapses global processes with bodily experiences, drawing a dialectic between suffering's social mechanisms with an individual's capable responses (Kleinman, Das, and Lock 1997, ix).

As the field encountered these perspectives, medical knowledge and institutions themselves became objects of critique. Critical medical anthropology (CMA) arose out of concerns about the “phantom objectivity” presumed about seemingly pure disease states (Singer 1989), which was previously adopted by biologically-oriented scholars and anthropologists (Brown and Closser 2016) who prioritized theories about “thrifty genes” and diseases of civilization with which to explain the distribution of communicable and non-communicable diseases such as HIV/AIDS as well as diabetes, heart disease, and cancer.

Instead, CMA-oriented anthropologists sought to understand how various diseases, and ecologically situated health anomalies around the world, could be linked to broader political-economic processes that shaped precise disease distributions and manifestations, such as AIDS in Haiti (Farmer 2006) and infant mortality in Brazil (Scheper-Hughes 1993). Pulling from these perspectives, the anthropology of disability has argued that disability is defined from the perspective of those who are “able,” and thus, those who are labeled as “disabled” are such because they “experience discrimination on the basis of perceived functional limitations” (Kasnitz and Shuttleworth 2001, 20).

Additionally, from the postmodern perspective, anthropologists sought to take an ethnomedical approach to understand how, rather than blindly privileging biomedical perspectives, different systems have varying *explanatory models*—that is, theories of disease which mediate how we conceptualize bodily states and the types of remedies utilized (Brown and Closser 2016). Such a process is mediated by cultural systems. In their seminal 1995 book, *Critical Medical Anthropology*, Merrill Singer and Hans Baer outlined how anthropologists taking up anti-medicalism (in contrast to the newly emergent political-economic leaning anthropologists described above) were reticent about “idealizing” biomedicine—which was

viewed as an inherently reductionist perspective, whose jurisdiction anthropology ought not help expand over determining illness, disease, and healing.

To accomplish this, Scheper-Hughes and Lock (1987) proposed their “three bodies” model in order to show how the body has been conceptualized cross-culturally and how these considerations serve to deconstruct the biomedical body. This branch of medical anthropology has drawn on scholars such as Mary Douglas, Emile Durkheim, and Michel Foucault in order to describe structuralist cultural systems, their internal inconsistencies, and their disciplinary functions, respectively. Recently, disability scholars have combined critical and postmodern arguments to position disability within a biopolitical regulatory field wherein disciplinary functions serve capitalist, neoliberal ideologies seeking to utilize (human and public) resources in the accumulation of capital (Mitchell and Snyder 2015).

Finally, the phenomenological approach examined experience-near approaches, also signaled by Scheper-Hughes and Lock (1987), which focus on subjective emotionality to articulate bodily and cultural experiences. For example, Arthur Kleinman (1988), borrowing the illness-disease distinction from Eric Cassell (1976), explicated the importance of capturing a patient’s illness narrative to understand the meanings surrounding illness, pain, and chronic distress. Through narrative, we may capture experience and its underlying meanings, which may illuminate disjuncture and tension in the sociocultural systems within which individuals are embedded. For instance, “baldness and impotence” denote one sort of undesirable cultural register while chronic pain, accompanied by stress, anxiety, and depression, can frustrate one’s struggle for freedom both emotionally and physically (Kleinman 1988, 25). As such, stigma, chronic pain, or any other illness experience is the result of that experience being expressed through symbols whilst being imbued with meaning (Brown and Closser 2016).

Together, these three perspectives have transformed theories of the body, its dis/abilities, and normative values both tacit and explicit. Political economic processes, the biocultural construction of disease and healing standards, as well as the distress and stigma that accompany transitions in bodily states are all entangled with one another. As such, each of these spheres has implications for the others. For instance, a phenomenon such as stigma cannot be disconnected from the processes of normalization that created it, nor from the political processes that legitimate it.

This dissertation defines disability as not only a condition of the body, but also an ethical standpoint wherein a focus on disability is both a field of study and a lens through which to critique larger society. This perspective is inspired by Cassandra Hartblay (2020) who argues that disability constitutes a field with political and ethical assumptions that is further altered by its engagement with, and a continuously building knowledge of, lifeworlds of those normatively deemed disabled. The recognition and questioning of ablenormativity as a normative lens by which we critique society is central in this dissertation as it informs the theoretical model that will be proposed in chapter 2 and repeated in subsequent arguments. However, such questions of how such paradigms guide our field of study are also relevant to how anthropologists have investigated stigma vis-à-vis disability and its chronicity.

Experience-near Approaches in Disability and Chronicity

Regarding chronicity, Howard Stein (1990) describes chronic illness as inherently stigmatizing as it comes into conflict with the aims of biomedical science. Namely, it defies attempts to influence the sick role thorough “problem-solving” to “repair the problem” (Stein 1990, 34). This is its rationality. Similarly, Byron Good (1993, 65) described how “medicine

formulates the human body and disease in a culturally distinctive fashion,” constructing reality with its own, by no means objective or inevitable, organizing principles.

Kleinman (1988, 161) delved deeply in describing the chronically ill and disabled as responding with shame (emotions characterizing stigma) in response to their family and health professionals. Thus, chronicity manifests in a double bind (drawing on Gregory Bateson and colleagues 1956), in which patients’ feelings of guilt are normalized alongside encouragements of independence and active care (Kleinman 1988). Not only do patients receive directly contradictory messaging, but these are concomitant with emotional and social turmoil, all of which “constitute the illness experience” (Kleinman 1988, 253). By the early 1990s, medical anthropologists dedicated to articulating chronicity identified how underfunded many programs geared towards chronic illness tend to be, often due to the overwhelming commitment and effort required, which stands in contrast to acute illness (Strauss 1990). For example, chronic illnesses such as disability seem to be situated between an acceptable narrativized public domain and a less acceptable experience-oriented private domain (West 1990).

More recently, Zoë Wool (2015) expands on this, describing this tension in terms of extra/ordinary—a fraught tension between quintessential masculinity and the injured body, the latter being experientially ordinary yet interpellated as immanently, extraordinarily injured and deprived. The discrepancies that spring up from such dichotomous relationships (i.e., ordinary : extraordinary :: public : private :: acute : chronic :: communicable : noncommunicable :: desirable : undesirable), are themselves social facts (Durkheim 1982). While medical anthropologists understand these dichotomies to be built on false premises due to their inherent links to social, political, and economic dimensions, we nonetheless understand that these rationalizations have shaped the kinds of bureaucracies, resources, and social lives in which

individuals with so-called chronic illnesses are embedded (Manderson and Smith-Morris 2010). In other words, a bureaucratic structure functions as if they were true, and this has served to render suffering invisible.

Centering disability in medical and cultural anthropology has served to contrast a normative “self” to a non-normative or perhaps stigmatized “other” (Clifford 1986, 23). For instance, regarding leprosy, Nancy Waxler (2016, 236) describes the process of social labeling, in which a person “learns to be... the kind of leper his family and neighbors, even his doctors, expect him to be.” Similarly, Linda Hunt (2016, 242) examines how illness narratives operate to “generate a strategically revised identity” that address internal cultural conflicts, serving to resolve some of the concomitant difficulties that may arise in a person’s life. In each of these cases, not only does an “other” exist, but those roles are simultaneously circumscribed yet capable of transformation.

This process is most evident in the work of Robert Murphy (2001, 86), who evidences that we dehumanize people with disabilities through our “selective blindness” that often renders them both invisible and outside of our cognitive awareness. Murphy uses psychoanalysis to describe how illness experiences such as paraplegia and quadriplegia, which he acquired due to a spinal tumor, change one’s notion of self through the body. For Murphy, biomedicine is implicated in these changes as it is incapable of dealing with an entire “self,” instead leaving certain aspects of a person’s psyche to be banished and abandoned. This process leads to the kind of depression and self-alienation he describes in his own disability experiences.

As such, people with disabilities are, for Murphy (2001, 111) “afflicted with a malady of the body that is translated into a cancer within the self and a disease of social relationships. They have experienced a transformation of the essential condition of their being in the world. They

have become aliens, even exiles, in their own lands.” Such explorations of subjectivity—often through pain and other afflicted experiences—have been taken on by anthropologists in a number of settings (e.g., Good 2012; Throop 2009, 2012; Hollan 2012).

However, such dynamics are also inherently social. For instance, Lenore Manderson and Narelle Warren (2010) articulate how trust – instilled through relevant dimensions of caregiving on the part of healthcare professionals – is a valuable part of the therapeutic relationship, particularly with disabled patients. Such relationships of trust – which involve communicating culturally relevant demonstrations of competence – are integral to promoting socially cohesive dynamics. Yet, as Cheryl Mattingly (2010, 86) articulates, there also exists a “paradox of hope” where African American parents of children with chronic health issues maintain hope – where they often must struggle against healthcare bureaucracy in order to push their children’s health outcomes forward – while carefully avoiding being labeled “noncompliant,” which brings with it stigma such as through justifications for ignoring their concerns. Thus, rehabilitation can bring with it a fraught social field in need of negotiation.

Socio-political Structures of Disability

In line with Marxian political economic perspectives of disability, recent scholarship on disability in anthropology has positioned physical afflictions such as paralysis and spinal cord injury as embedded in macro-economic systems of inequality. For instance, Laurence Ralph’s (2014, 15-16) research with gun-shot victims in Chicago links communities of “urban poor” with the communal projects intended “to assuage their myriad injuries.” This focus on macro-level divestment of community resources (especially in African American communities) combined with specific ground-level actions helps illustrate how disability is defined and understood in the

US and around the world (Ingstad and Whyte 1995). Such research thus centers political economic processes in conjunction with critiques about normative standards they reify.

Similarly, Molly Bloom (2019) has described how wheelchair basketball players (with paraplegia) construct “narratives of competence” which serve not to reject their disability, which would merely perpetuate the stigma of disability, but rather construct themselves as capable. Again, this research questions normative narratives about disability, this time centering recreational and social activities. Indeed, the anthropology of disability is as concerned with the precision of narratives as it is about the power structures that undergird their rhetoric—namely, to endorse either passing as able-bodied or at least taking responsibility for promoting a rehabilitation narrative of overcoming (Rembis 2013). Bloom exemplifies the process of “social relabeling” articulated by Waxler (2016) above; however, such discursive acts always signal an underlying cultural model—in this case, difference, and thus, stigma.

Indeed, difference and stigma can also be reinforced through environmental barriers and lack of inclusive spaces. Rattray’s research on disability in Ecuador highlights the implications of policy that seeks to create inclusivity but where—from a perspective that perpetuates difference, social stigma, and spatial isolation—“social practices with transportation systems shape the boundaries between able-bodied spaces and terrain constructed as inaccessible” (Rattray 2013, 26). For instance, spatial isolation is reinforced through cultural, normative attitudes of shame which both reinforces marginalization while also granting disabled Cuenqueños the ability to contradict such paradigms through rallies and marches.

Here, the built environment serves as a field where differences are enacted, reinforced, and even naturalized, while also creating ideal conditions for activism. Recent writings on affordances in disability highlights the human-environment interaction as shrinking for people

with disabilities, necessitating these kinds of “microactivist” actions (Dokumaci 2020, S99-S100). Considering that access and environmental barriers are a main concern for people with disabilities, highlighting these structural inadequacies is relevant to ongoing concerns for creating inclusive public spaces for people with disabilities.

Disability research here tends to highlight how community, recreational, and infrastructural dimensions tend to illuminate an ethic of disability – that is, what such systems communicate about how disability enables (socially) and regulates/distributes individuals (via biopower). If Ralph (2014) situates disability’s neighborhood divestment to highlight racial and economic inequalities, and Bloom (2019) situates disability’s everyday practice and narrative sociality in order to highlight its normalization in quotidian experience, then Rattray (2013) highlights well-meaning attempts at inclusivity that still serve to reinforce these (harmful) normative standards.

As such, this dissertation will analyze social structural norms at a rehabilitation site in order to perform this same work, where I juxtapose intentionally well-meaning plans (the narrative life of morals) from actual norm-reinforcing outcomes (ethics as an ethos of normative practice), revealing the “wild policy” inherent in such bureaucratic program development (Lea 2014). Ian Buchanan (2020, 123-124) critiques the tension between policy makers’ intentions (which do not consider harmful unintentional consequences) and the actual constraints placed on these policies themselves (which form how policies get enacted). Understanding how the materiality of social assemblages interact with cultural narratives helps untangle the various data with which this dissertation engages, as SCI rehabilitation is filled with disability narratives along with ever-shifting policy dynamics that create both gaps and affordances in pwSCI’s lives.

The Social Model of Disability: Rehabilitation and Return to Work

These issues of difference and stigma are further exemplified by disability studies scholars who describe the American with Disabilities Act (both its 1990 and 2008 iterations) as “an immense vehicle of legal power,” which has serious consequences for people with disabilities (Skyer 2019). They argue that this occurs through its capacity to solidify a view of disability as ill-health rather than as a category constructed by the intersectional contexts in which it exists (Staples and Mehrotra 2016). This critique of the ADA does not suggest that people with disabilities derive no benefits from it, but rather that it reinforces a largely ableist set of norms—for instance, that disability can be purely defined as a lack of function, rather than as a set of practices that serves to stigmatize and pathologize persons with disabilities. To address this, disability scholars have combined these critical perspectives with traditionally postmodern ones.

This serves to describe the historical trajectories that have placed disability policies and efforts as needing to confront “consumptive technologies of the body,” in which “bodies diagnosed ‘debilitated’” are marked “as opportunities for new product development and market expansion” (Mitchell and Snyder 2015, 11-12). Recently, Jasbir Puar (2017) has centered ‘debilitation’ in her research as a means of bridging the abled/disabled dichotomy by focusing on disability as a highly contested process. Debilitation as a process highlights how a person experiences a foreclosure of rights due to the contested and imprecise nature of disability definition and policy—i.e., *disability* as denoting access (or not) to much needed rights and accommodations.

Such considerations reflect shuffling standards of *biological citizenship*, which Adriana Petryna (2004, 261) defines as “a demand for, but limited access to, a form of social welfare

based on medical, scientific, and legal criteria that recognize injury and compensate for it.” Legitimacy to such social welfare claims is contingent on loss of primary resources (e.g., employment) and social standards of deservingness that create a consensus over legitimacy of such claims. Such dimensions of difference, however, inevitably become problematic as they are linked “to beliefs about the biological existence of human beings,” despite a claim to objectivity (Rose and Novas 2005,440). Thus, how the body is defined is shaped by ideological standards and its political impetus.

Furthermore, Loïc Wacquant (2012, 76) fuses considerations of governmentality with hegemonic political economic systems by linking market liberalism with its inherent, “punitive paternalism” for those at the bottom. This is akin to the double bind-like dynamic described above that simultaneously includes people with disabilities while excluding them by placing them firmly in the for-profit medical complex, particularly in the United States (Mitchell and Snyder 2015). There also exist SCI-related bureaucratic discourses surrounding a governance and biopolitics (Foucault 2008) of pwSCI that situates injured bodies within a complex that seeks to extend, maintain, and expand their lives and livelihoods through various means and often through coercive techniques of power (Foucault 1991).

Disabled bodies have been evaluated as lacking, in need of rehabilitation, and defined as being socially and economically unproductive (Mitchell and Snyder 1997). This is especially relevant considering the bureaucracy surrounding SCI that unquestioningly enters people’s lives and extracts personal and intrusive information, simultaneously defining those deemed “fit for social participation” while naturalizing their status (Bridges 2017, 11). After all, defining features of pwSCI are varying degrees of in/dependence, psychosocial well-being, and traumatic experiences (Etingen et al. 2018; Kennedy & Garmon-Jones 2017; Ruan & Luo 2017).

PwSCI are largely influenced by the biopolitical regime that seeks to re-integrate them into ableist and capitalist notions of productivity, employment, and well-being, prioritizing their utility in capitalist culture— what David Mitchell and Sharon Snyder (2015) refer to as *ablenationalism*. A main feature of ablenationalism is that new forms of acceptance serve to reify the value of normative ableism. As such, “overcoming” narratives that prioritize ability over disability characterize ablenationalism. Thus, rehabilitation is further implicated in practices of conformity for the broader goals of servicing a nation-state. Primarily, ability is normatively linked to citizenship in ways that devalue disability.

For example, one of the benefits of qualifying for Social Security Disability Insurance programs is qualifying for its Ticket-To-Work program, which incentivizes people with disabilities to work in order, for instance, “to improve their earning potential” (Social Security Administration n.d.). However, considering that such resources exist at the federal level and not necessarily at the state, exercising those rights to work may also inevitably lead to people experiencing “discrimination on the basis of perceived functional limitations” (Kasnitz & Shuttleworth 2001, 2).

Furthermore, disabilities are heterogeneous, as is evident in what we might call the ‘D/deaf community’ where, while living in relative isolation and bringing about concerns surrounding resources access and acquisition (Bodemann 2012; Terry, Lê, and Nguyen 2016; Asonye, Emma-Asonye, and Edward 2018), the lack of a function (hearing) also gives a person the chance to belong, voluntarily, to this particular community (Drolsbaugh 2008). In comparison, mobility-related disabilities such as SCI have different challenges, which are rationalized as occurring due to their relative lack of independence as well as the several secondary conditions that commonly accompany injury including pressure ulcer risk, chronic

severe pain, and respiratory complications that affect life experiences and psychosocial well-being (Brienza et al. 2018; Burns, Wilson, & Craven 2013; Dijkers et al. 2009; Hagen & Rekand 2015). A main point throughout this dissertation will be to interrogate the notion of in/dependence that often qualifies SCI as an extraordinary disability among all the disabilities. SCI is indeed heterogeneous with various levels of dependence characterizing. As such, the notion of caregiving is especially relevant to SCI.

Anthropology of Caregiving and Social Support

Implicated in this as well are notions of social support for pwSCI, which has been identified as greatly modifying depression, feelings of hopelessness, and even serving to predict early mortality (Kennedy & Smithson 2013; Krause & Carter 2009). It is common for family members to assume primary caregiving roles, providing care in the form of bathing, dressing, and taking medications, to tube feeding and ventilator care (Reinhard et al. 2008). Moreover, these caregivers also enter this new role with little guidance or education regarding financial strain, maintaining quality of life, and health and emotional issues (Kennedy & Smithson 2013). This kind of informal caregiving may not be viewed as an occupation, despite the time and effort required to care for patients at home (Lin et al. 2018).

Considering the amount of physical, temporal, and emotional labor involved in caregiving, this is another level in which ablenationalism comes to define those surrounding people with disabilities also as unproductive (Mitchell and Snyder 2015). Furthermore, informal domestic care tends to also be gendered, as noted in anthropological and feminist scholarship in disability, with women taking on a larger share of these roles (Boris and Parreñas 2010). This is especially contradictory as family caregivers also face issues of financial strain and opportunity

costs including professional or economic opportunity, such as if the caregiver must forgo or cut back on work hours to provide care at home (Lin et al. 2018).

In addition to these, this dissertation defines care as a practice instituted by health practitioners as well. Thus, care pertains here to both formal and informal, personal and institutional, spheres of care. Therapists and physicians institute their own logics of care, and these become differentially coordinated depending on whether ‘care’ or ‘choice’ is prioritized (Mol 2008). Furthermore, “care work being performed by caregivers is increasingly medically complex, ongoing, and intertwined with and using knowledge and tools associated with science, technology, and medicine” (Mauldin 2017, 143). Thus, these considerations also intersect with issues in science and technology studies (STS) of disability.

Science and Technology Studies of Disability

STS has approached disability studies from several theoretical perspectives, especially social constructivism and actor-network-theory (ANT). Through these two perspectives, it examines how technology is used to ‘fix’ bodies and effectively extend the biomedical gaze that anthropologists of experience articulated decades ago (e.g., Good 1993; Hollan 2012; Kleinman 1988; Scheper-Hughes and Lock 1987; Throop 2010a). Alternatively, STS-disability scholars explore how society and technologies, with people with disabilities at their nexus, are co-constituted as actors within a dynamic network. STS as an approach and perspective traces its roots to Thomas Kuhn (1962), who positioned scientific facts as socially contrived products. This perspective, along with theorization of “paradigms” and “paradigm shifts,” has been borrowed in anthropology to denote “bodies of assumption” in both culture and within the discipline (Yelvington 2011, 64-65).

Notably, many concepts within STS also borrow from postmodern skepticism and social constructivism. Thus, many of the issues outlined above focus on assistive technologies, space, and access/transportation and their dis/abling effects (Galis 2011, 826). There is also a broad scholarship utilizing ANT (Latour 2005), which combines human-nonhuman actors within a relational ontology that highlights connections over identity or determinism by any kind of actor. To that end, STS-disability scholars have noted the prevailing exclusion of people with disabilities in processes of design, shifting the conversation towards identifying exclusionary practices of public design rather than merely the design itself (Galis and Lee 2014).

At the same time, disability studies has pushed against the medical model of disability, which describes individuals as pathological and defective (Brown 2015). Instead, a social model of disability locates impairments not in the people themselves, but in our structures and culture which renders them both invisible and subordinate with limited access to buildings, transportation, and communication (Ralph 2014). Mitchell and Snyder (2015) have defined these opposing perspectives as “two zones of negativity,” otherwise known as the impairment-disability divide (Longmore 2016).

Meanwhile, anthropologists have described how illness and disease work cyclically, with cultural infolding into experience through illness, which then unfolds into social space (Kleinman and Kleinman 1996). Through this lens, the impairment-disability framework is a biocultural construction wherein bodies may become disabled, but where we culturally construct a doxa about the nature of disability that normalizes a pathology of a disability perspective. This is currently a field of inquiry that is being negotiated by disability scholars (Shildrick 2019).

Within STS, the relatively new term *biomedicalization* denotes broader forms of bodily and symbolic transformation through various technoscientific means, such as assistive

technologies (Clarke, Shim, Mamo, Fosket, and Fishman 2010). Adopting ANT, these scholars describe how non-human actors (objects) within these networks may delegate and organize human behavior. Furthermore, STS scholars have also denoted that technologies including techniques of calculation for bureaucratic expediency, such as disability calculation systems designed to manage disability entitlements, may actually inhibit quality of life in favor of governance (Admon-Rick 2014).

This has resonance in anthropology, which has examined how the quantification of health has led to processes of community alienation (Stevenson 2014) and dehumanization (Yates-Doerr 2015) in communities positioned outside of a more normative national identity. This has raised questions about what we give up when we ‘black-box’ disability classifications that are then charged with granting “civil identity,” mediating important benefits on which individuals rely (Admon-Rick 2014, 124).

While STS has adopted these social constructivist and ANT-oriented perspectives, generally, social constructivist perspectives have been criticized as discriminating against non-human actors by ignoring their potential to drive behavior (Latour and Woolgar 1986), while ANT has received criticism that its privileging of network formations, and its “disinterest in power asymmetries,” account for *what* rather than *how* (and to what degree/magnitude) these interactions occur (Galis 2011, 830). Indeed, a main focus in STS-disability scholarship is the privileging of normalization that the use of assistive technologies attempts to perform (by seemingly equalizing ability) at the cost of making our social structures more inclusive (Mauldin 2017). Thus, we require a theoretical scaffolding that includes the what (objects), the how (their mechanisms), and how power is implicated in this dynamic.

Rather than seeing “evidence” and “practice” as straightforward concepts, and actors as necessarily privileged, this dissertation uses an approach in STS that allows us to understand how the differences between two rehabilitation centers, centers that we imagine must accept the same kinds of evidence, are ontological. In fact, this is how Annemarie Mol (2002, viii) articulates “care” in a Dutch hospital where she describes the error that occurs when we define concepts like “care,” “health,” “disease,” or “body,” as well as other objects, as if they could be abstracted identities outside of their processes—the practices that enact them. Instead, we should see what happens when, in terms similar to Boas’, we refuse to treat qualities as “concrete substance[s]” (Boas 1940, 598) and instead see how practice makes these fundamentally distinct from one another (Mol 2008).

Temporality and Spinal Cord Injury

As discussed above, the medical anthropological literature has approached illness experiences as highly contested, including in political spheres. In such cases, time and its management “becomes a tool for social control” (Ferzacca 2010, 157). “Time and timing are social resources that are unequally distributed within a socially stratified group—some members of the group have more control and access to the uses of time and timing than others,” thus creating a “chronopolitics” (Ferzacca 2010, 158). Through therapy, power is more or less wielded through notions of chronicity (time) that serve to naturalize an unending chronic condition that limits biomedicine’s ability to cure its patients (Stein 1990). However, most research has focused on other diseases such as diabetes and cancer and have yet to be applied to SCI in particular.

Alternatively, the epidemiological literature contains a wealth of data on longitudinal experiences of SCI, giving us valuable information on how SCI experience may shift over time.

For SCI, a complete injury means that there exists no motor or sensory function below the level of injury, while an incomplete injury means that there is at least partial motor or sensory function—however, we also know that depending on injury severity, over time, some people can fully recover and regain full sensory and motor functioning (Palimaru et al. 2017; Teufack, Harrop, and Sharan 2013). The American Spinal Injury Association (ASIA) Impairment Scale is a tool used by clinicians to assess and track injury for those with SCI and has been greatly beneficial for classifying injury types and changes.

The specific context of these relationships requires further investigation. For instance, despite the various gains in life expectancy over the past several decades, age at injury has been shown to significantly mediate the development of secondary medical conditions (such as pneumonia) for those aged 60 or older who encounter SCI (Chen, He, and DeVivo 2016; DeVivo et al. 1990; DeVivo and Chen 2011). Time since injury has been another controversial predictor of health and well-being in pwSCI due to the imprecision of any causal mechanism. Older ‘stage theories’ hypothesized that length of time was necessary for individuals to adjust to their new way of life (Guttman 1976).

Indeed, research has repeatedly found that less time since injury is associated with decreased quality of life, more depressive symptoms, and increased life restrictions (Müller et al. 2017). However, others suggest that these findings may be contingent upon one’s ability to manage secondary health conditions such as pain, spasticity, pressure ulcers (Adriaansen et al. 2016; Stillman et al. 2017), and autonomic dysreflexia-inducing bowel dysfunction (Inskip et al. 2018)—all of which require time for people to adapt. As such, quality of life and other scales may more directly be associated with pain and discomfort, medical interventions, and lack of independence, all of which are negotiated and may become more manageable over time.

However, each of these approaches takes a purely psychological or physicalist perspective on understanding quality of life and self-reported well-being. As a result, researchers have also focused more on how cognitive appraisals of adversity can mediate one's adjustment to injuries and livelihood (Dean and Kennedy 2009; McDonald et al. 2018). Cognitive appraisals are interpretations that we make to any given stimuli, thus situating it outside of one's head. With regard to SCI, these include self-blame, uncontrollability, threat, negativity, and challenges to social and therapeutic participation—all of which have been shown to predict present and future adjustment to SCI and are linked to quality of life (deRoos-Cassini et al. 2013; Mignogna et al. 2015; Peter et al. 2014; Van Leeuwen et al. 2012). A rich ethnographic study that applies anthropological perspectives of chronicity towards SCI research could capture more nuanced notions of well-being, quality of life, and depression that would help contextualize the epidemiological literature.

Overview and Critiques of SCI Institutions in the US

For most of history, SCI was “an ailment not to be treated,” with virtually no one surviving more than a few months, including US President James Garfield and US General George Patton, both of whom, by today's standards, had relatively low paraplegia-level injuries (Donovan 2007, 85). This attitude coincides with the institutionalization of patients, inmates, and clients within hospitals, prisons, and asylums through the nineteenth and twentieth centuries (Gawande 2014), which served to include people with disabilities within these institutions of structural exclusion (Noll 2018). In other words, institutionalization of disabled persons served to cast them aside and render them invisible, effectively leading to a lack of concern with addressing their situations. Indeed, this was similarly performed on the elderly and infirm during these same periods (Gawande 2014).

In the US, President Franklin D. Roosevelt's New Deal legislation regulated the kinds of benefits that people with disabilities could receive, simultaneously ensuring benefits as a result of their unemployability yet "further marginalizing their employment opportunities and reinforcing their dependence on the state" (Patterson 2018, 440). Through this context, disability rights activists sought equal access and inclusion primarily in work participation. Many of the right to work policies and priorities have arisen out of these early civil rights efforts.

Regarding physical disabilities, while scholars show how race and socioeconomic status (SES) determined who could claim independence and rehabilitation opportunities (Patterson 2018), recent studies have revealed enduring disparities, with ethnic minorities and people with lower SES being far more likely to experience adverse health outcomes and to receive different treatments (Dru et al. 2019). Thus, throughout much of the Twentieth Century, activism focused on physical disabilities failed to maintain sustained efforts in challenging these ableist provisions concerning disability work rights. Nonetheless, after World War II, people with various physical and mental disabilities participated in the labor market, bolstering activism and increasing recognition of their human rights (Patterson 2018).

In the 1960s, disability civil rights activists fought for physical access and the construction of "barrier-free environments," seeking to address how federal and state governments could help society accommodate people in wheelchairs, or other so-called limitations (Patterson 2018, 444). By 1968, all but three states "lacked a formal effort to pass architectural barrier legislation," with parallel disability legislation in Canada and Great Britain being passed around the same time (Patterson 2018, 444). Throughout the 1970s and into the 1980s, independent living facilities grew rapidly, displacing the institutionalization of much of the nineteenth and twentieth centuries. The 1980s also saw racially diverse disability groups that

led some to refer to this decade as “the golden age of disability legislation”—yet rights to rehabilitation and Social Security were also revoked at this time, further complicating matters for pwSCI (Patterson 2018, 450).

Much of these efforts culminated in the period between 1988 to 1990, leading up to the Americans with Disabilities Act. Moving beyond a focus on physical barriers and discrimination, activists sought a more comprehensive legislation that would address some of the fundamental issues plaguing the lives of people with disabilities (Patterson 2018). While the Civil Rights Act of 1964 did not include provisions for people with disabilities, the Americans with Disabilities Act of 1990 opened up these previously foreclosed opportunities (Donovan 2007), such as extending antidiscrimination to private institutions and businesses offering public services. However, due to the narrow interpretation of the 1990 ADA legislation, nearly twenty years passed before many of these issues would be fully executed in the 2008 ADA Amendments Act legislation (Patterson 2018).

Notably, SCI has simply moved from something to be maintained, to treated to modern concerns with curing it (Donovan 2007), which disability activists posit as simply reifying normative ableism within our society that renders pwSCI as politically and structurally debilitated (Ralph 2014; Puar 2017). Indeed, the history of disability and SCI in the US has revolved around including pwSCI within an ableist paradigm that prioritizes return to work as the primary definition of social reintegration. Likewise, many institutional concerns have revolved around extending pwSCI’s ability to participate in so-called normal life with increasing funding being allocated for SCI research.

Thus, a chasm in the SCI literature separates those who designate SCI as a sphere where medicine has served to enhance the lives of those who are physically, socially, and functionally

impaired, hoping to one day cure this ‘disease’ (e.g., Donovan 2007; Lifshutz and Colohan 2004), and movements (including within the anthropology of disability) that hope to highlight and challenge the naturalization of an abled and normal body in our culture (Kasnitz and Shuttleworth 2001; Ginsburg and Rapp 2013). This impairment-disability divide (Longmore 2016) is especially poignant for pwSCI, whom Sarah Phillips (2011, 2) describes as feeling in a state of perpetual liminality due to having been given a purported “license to do nothing.”

This research is situated in these philosophical and institutional approaches to SCI, understanding, following Moya Bailey and Izetta Mobley (2019, 28), that, “As uncomfortable as it may make those of us engaged in the Disability Studies field, some communities are actually yearning for not only care but treatment and cure.” Thus, the tension between cure-seeking and building an inclusionary society are largely non-existent for those with disabilities themselves – which is not to say that policy foci on one or the other are not consequential to their lives. With pwSCI placed squarely in the middle of both moralizing and normalizing discourses regarding SCI embodiment, this dissertation proposes an integrative approach to material-semiotic assemblages that can enhance how we study this complicated analytical field.

Chapter Two: Theorizing Affect and Governmentality in SCI Rehabilitation Experience

Whether we think of disability anthropology as focused on challenging normative experience, normative structures, the metaphysics of care, or biopolitical processes of control, without a robust theoretical and methodological framework, the background described in Chapter One leaves open many gaps in need of bridging. Specifically, gaps between impairment/disability, dependence/independence, and inclusion/exclusion. In this chapter, I seek to conceptualize a theoretical approach that draws heavily on the works of Michel Foucault and Gilles Deleuze—two scholars concerned with how humans create normative structures that influence their lifeworlds.

What is normal, natural, and primary? These are each loaded concepts that anthropologists regularly complicate through critical and social deconstructionist approaches. For instance, Deleuze (1994) and Foucault (1970) each focused on the structures of thought—those normative assumptions and categories that we create before we initiate thought. This innovation is central to this dissertation as it suggests that interpretations are not only subjectively contingent on the interpreter, but also conceptually contingent on the interpreter's own ethical stance. Indeed, assumptions precede knowledge. This issue is particularly important for thinking through disability scholarship—which focuses on a population considered “the most discriminated [against] minority in our nation” (Burgdorf 2015). However, how we construct such categories (and conceptual umbrellas such as “disabled”) requires interrogating our own theoretical lenses as these are our first normative structures.

The Deleuzian/Foucauldian “Method”

These structures of thought are best laid bare in Deleuze’s (1994) *Difference and Repetition* where he explicitly questions the normative metaphysics that leads us to relegate difference under the principle of identity. That is, that when we compare any two things (concepts, cultures, or even categories of social identities), we often grant that object an inherent identity. Thus, identity categories/markers such as “disabled,” “queer,” “Black,” and “woman” are seen as objects capable of being blended and combined. Importantly, the concept of intersectionality within critical race theory has required further elaboration in the last decade in order to combat such commonsense interpretations. “Oppression Olympics” is the epistemological trap CRT scholars identify, “in which contested unidimensional constructions of oppression compete with each other” (Yuval-Davis 2012, 52).

However, this serves as an epistemological dogma that reinforces the interpretation. In other words, how we conceptualize such identity *as* unidimensional in the first place drives the Oppression Olympics practice. This point is poignant given how some ontological turn (OT) scholars have created hyper-identities. For example, Eduardo Viveiros de Castro (2011, 165), with his “tactical quintessentialism,” thinks difference predicated on identity, but a seemingly infinite conception of it.

To take the ontologies of others seriously, this move by OT scholars is meant to state that differences on every level matters so much, and that we cannot flatten our cultural analyses by likening one culture in the same terms as another—this is perhaps what might be called a neo-ethnocentrism (Candea 2012). We must flesh out a cultural trait within its own ontological sphere (illuminating its own ontological terms), a process that complicates ethnological analyses. Deleuze’s argument goes that “With Aristotle, Philosophy was able to provide itself with an

organic representation of difference, with Leibniz and Hegel an orgiastic representation: it has not, for all that, reached difference in itself” (Deleuze 1994, xv). OT scholars creating an endless stream of essential identities falls under this “orgiastic” designation.

However, Boas (1940, 598-599) explains that in a culture, “the more distinctly a quality is conceived as a concrete substance, the less will its existence be bound up with the object possessing the quality in question.” In other words, we threaten to “turn names into things” (Wolf 2010, 3). The OT inclination to construct an endless number of things does not solve the core issue. This has resonance with Geertz’s move towards processual culture, accusing piecemeal, instrumentalist definitions of culture as obscuring “a good deal more than it reveals” (Geertz 1973, 4). Geertz moves towards a concept of culture that centers symbols to highlight the objects that contain representational and productive weight—all things that happen in the ethnographic context of the event rather than being localized anywhere or in anything.

This is instructive for the theory described here because it illustrates the weight of analytical models. In much of anthropological theorizing, we have struggled to move beyond the epistemological trap that CRT scholars addressed vis-à-vis intersectionality and the oppression Olympics phenomenon. Constructing more identities or more variables does not challenge the implicit dogma. For instance, Deleuze (1994, xvi) critiques the “images of thought,” where:

(1) we suppose that thought possesses a good nature, and the thinker a good will (naturally to 'want' the true); (2) we take as a model the process of recognition - in other words, a common sense or employment of all the faculties on a supposed same object; (3) we designate error, nothing but error, as the enemy to be fought; and (4) we suppose that the true concerns solutions - in other words, propositions capable of serving as answers.

In short, we construct identities (thereby unwittingly creating a dogma) because humans create orthodoxies and dogmas rather than pure objective truths. Rather than attempting to find right

answers, we ought to first question the way of thinking that created that proposition in the first place.

Indeed, disciplinary dogmas delayed the study of emotion in the social sciences as it was considered “a private, biological, or psychological phenomenon not governed by social rules” (Loseke and Kusenbach 2008, 511). Despite theoretical engagements of emotion’s sociality (being engaged by scholars from Aristotle to Darwin, Freud, and Marx), empirical foci on emotion’s sociality were largely relegated to psychology until later being thrust into the realm of sociocultural contexts (such as by the Culture and Personality School of Boasians like Mead and Benedict). Until then, emotions were considered by some social scientists to be human universals where “people’s feelings in the past did not differ from those in current eras” (ibid.).

Such recognition is relevant as it illustrates how social constructionism can influence the very research that attempts to theorize it. In other words, disciplinary dogmas can also be deconstructed. Such an understanding pushed Foucault (2008, 3) to take on an inductive method: rather than assuming something like sexuality or madness exists, what would happen if we started from practice itself, presuming “that universals do not exist”? This has been the best attempt at creating a new “image of thought,” separate from the identitarian program. We often make the mistake of presuming the existence of a thing, like government, rehabilitation, or addiction, but we must reject the inclination towards universals and start in how these things are instituted in practice.

Per Deleuze, our conventions clothe and obscure the dogmas that structure our thinking. This occurs through repetition. For Deleuze, difference is inherent in repetition because relations always synergize over time. Deleuze (1994, 18) inverts Freud, arguing that “we do not repeat because we repress, we repress because we repeat.” We repress that which does not allow us to

experience it (an event, an identity, or even an emotion) as a “bare” repetition, which makes up a particular form of *unconsciousness*. Thus, our inclination to create pure identities and objects conflicts with how relationalities fluidly and constantly shift. Humans construct institutions that reify certain norms; however, the fluid natures become obscured because in each iteration of a repetition, new relations are created and subsequently magnified. Synergizing. Polarizing existing relations. We construct rational systems that repress what still emerges in our ethical spheres. What is tacitly ignored, or actively suppressed? This is precisely what Foucault (2008, 16) argued about governmental rationalities (governmentalities)—that they deal not with natural rights, but with governmental practices which links to an entire philosophy about the management of human action, bodies, and the law. Such rationalities are far from purely natural and tend to leave a great deal obscured in order to function most effectively.

By following this Deleuzian/Foucauldian “method,” we must question the “natural” figure of the unconscious and place it firmly in a cultural context. Indeed, psychological anthropologists have long critiqued how ethnological data contradict any claim to an ultimate, natural, biological cause or unconscious (Quinn and Mageo 2013, 3). What is unconscious is constructed. And here, Deleuze defines the mechanism as the process of repetition itself where components synergize and whose relations (the product) must be external to their causes (i.e., the assemblage). Rather than meaning that there exist no internal relations (as understood by Campbell 2019), this means that we cannot look to individual components to understand a given product.

This argument aligns with Geertzian interpretive anthropology as Geertz’s semiotic definition (and empirical approach) of culture acknowledges the eclecticism of previous definitions that sought to locate culture in objects, behaviors, education, and even in

anthropological theory – an approach he called “self-defeating not because there is only one direction in which it is useful to move, but because there are so many” (Geertz 1973, 5).

Additionally, relatively recent theories of entanglement (Nading 2014) and syndemics (Baer, Singer, and Susser 2013) use this very understanding of human relationalities to argue for holistic solutions to holistic biocultural problems. In each of these, attempts to predict are shelved in favor of more integrated research programs.

Repetition itself is granted generative power here, and not some supposedly original form or event that we have simply forgotten.¹ Over time, synergies create real difference. Repression through the use of rational systems doesn’t result from forgetting (or error), but from a repetition itself which has some organizational power. Repetition instills an orthodoxy. Thus, there are no identities, but things take on new meaning with each iteration due to its relation to difference itself, which is generative and positive (i.e., productive). *There are no conceptual identities*, but we mistake differential mechanisms with difference between two identities.

Primary Affects and Secondary Rationalizations

In this dissertation, I define emotions as a culturally intelligible and definable state and affect as a bodily feeling or inclination that can be both felt physiologically and is often reasoned to be primary and automatic. I agree with Papoulias and Callard (2010) that affect and emotion

¹ At the risk of going too far into philosophy, Deleuze argued that our thinking was infected by Plato, and the history of philosophy has never been able to break out of the dogmatic image of thought. Indeed, elementary school curricula in the US spends time teaching students to distinguish between objects: to separate the fruit from the vegetables from the inanimate objects, for example. The concept of “fruit” floats vaguely above our heads like a Platonic Form/Idea, which is the core, originary, genetic origin of the concept. However, for Deleuze, there is no object that granted seeds of itself to its variations. No true “fruit” from which all fruit derives. Instead, through repetition, relations are able to synergize and discover difference. This is difference-in-itself. Difference predicated on notions of identity only pantomime difference, believing in the image of thought rather than discovering the mechanisms of difference in everyday life. However, we often miss this because, as we have our image of thought (where difference is predicated on identity), we actually believe in the absurd idea that repetition is “bare” (i.e., capable of being a full, faithful copy of an original form), which misleads us down false analytical pathways.

have considerable overlap. Ruth Leys (2011) convincingly argues that this overlap makes any conceptual separation untenable. However, unlike those she critiques, who define affect as pre-individual and raw universally human bodily reactions, I argue that affects are made to be normative, and once this occurs, can often be unquestioned; unlike emotions, which are more easily capable of being objectified and disconnected from our selves. In other words, affect has an air of originality and naturalness, but it is equally as created by social processes. Despite the overlap between affect and emotions, I believe the normative quality of affect is useful as it lends itself to a powerful social life where it is often unquestioned.

To help navigate between these, this dissertation introduces a tripartite theoretical framework (Figure 1) for helping think through how to translate these data into anthropological insight.

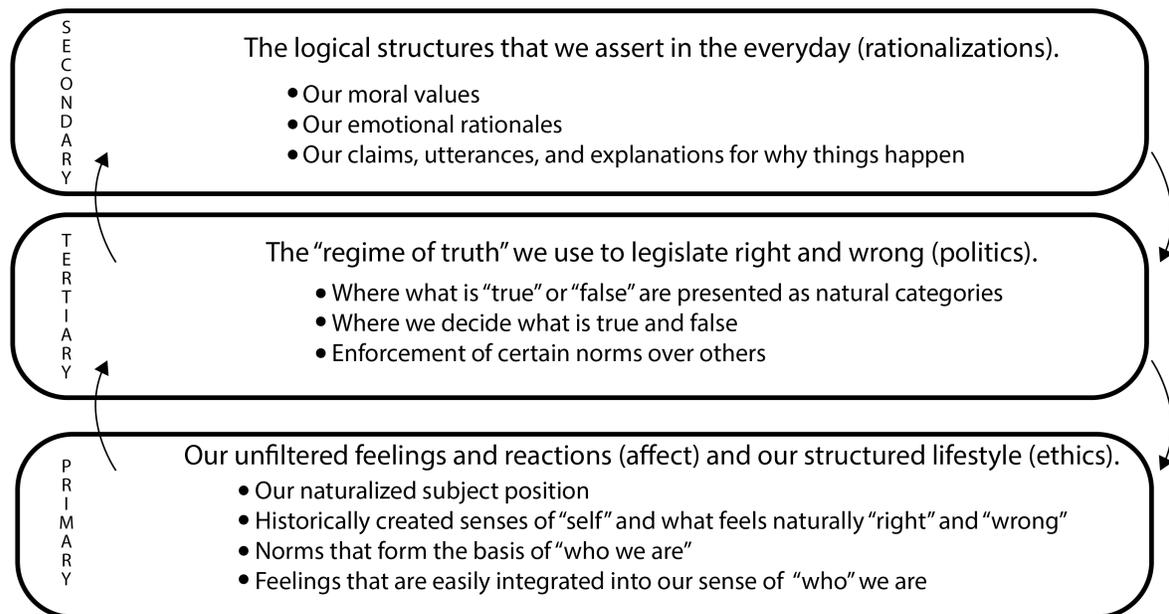


Figure 1. Three Level Framework.

I argue that this three-level approach gives us a way of structuring how we go from what we might call primary, historically predicated ethical affects (primary level) to secondary everyday

rationalizations (secondary level)—through a legislative (e.g., political) structure (tertiary level). I present two versions of this model. In this first, arrows on the left of the framework below indicate that much of our logical structures stem from our historically predicated subject positions. However, the arrows on the right illustrate how our everyday experience also helps shape our lives (and hence, our future histories). This model should first be read from the bottom up, then from top to bottom.

In this second representation of this three-level model (Figure 2), I visualize how culture enters the body, creating rational expressions.

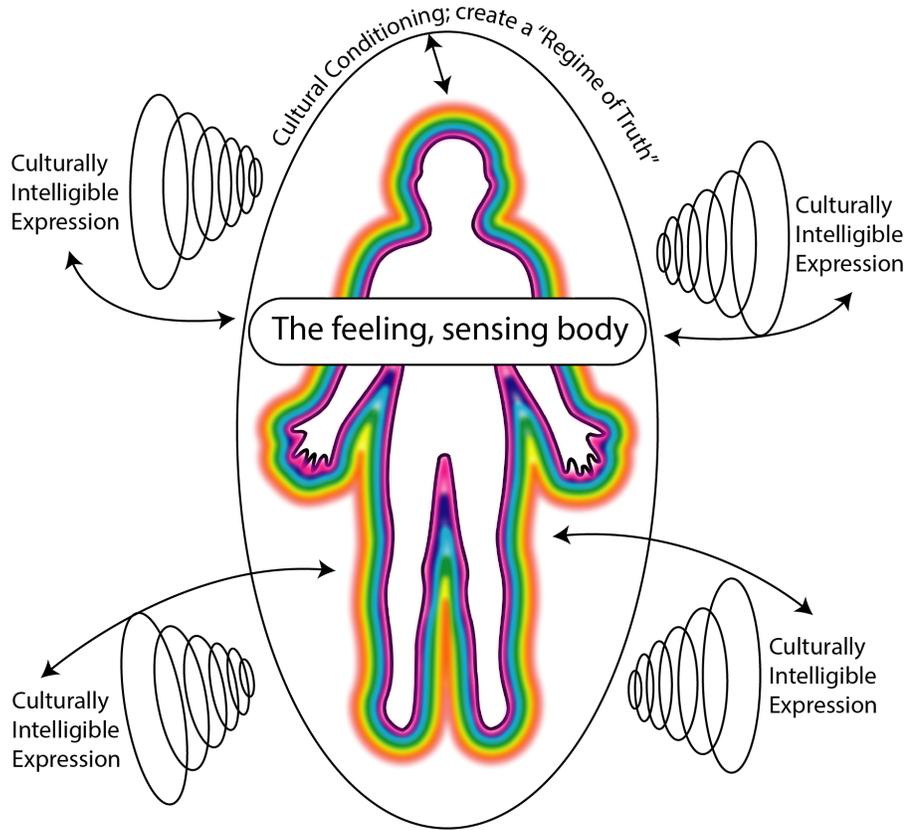


Figure 2. Interactive Three-Level Framework.

It starts with a feel, sensing body, which is shaped and molded by cultural concepts and conditioning, which, borrowing from Foucault, I call a “regime of truth.” As a result, what I call

“culturally intelligible expressions” are utterances that make rational sense within a given regime of truth. This regime is designated by the biomedical apparatus (especially regarding disability and chronicity), which operates within a given cultural paradigm that designates the terms of what is capable of being legislated as true or false (Foucault 2008; Good 1994). Thus, culture spills out and projects from the body. However, our interaction in the world (i.e., via repetition) can also produce differences within the body, transforming affects, senses, and perceptions. This feedback loop thus makes change an inevitable part of our cultural processes.

Returning to the theorizing earlier in this chapter, the example above on how beliefs about emotions limited social scientists from fully exploring their social nature constitutes a legislative structure that limited research in some areas and amplified research in others, creating a (tertiary level) regime of truth. Regarding SCI rehabilitation, this dissertation will analyze the narratives about injured bodies, activity-based therapy (the dominant therapy philosophy at my research site), and “recovery,” which I argue inhabits the secondary level rationalization. Various case studies outlining such narratives are introduced in chapter four.

However, what structures made these logical expressions the conclusion reached? In chapter five, I outline the various moral and bureaucratic processes that serve to direct and constrict the life and therapy goals of pwSCI there. In chapter six, I discuss ethical affects – which situates affective expressions as ways that pwSCI and rehabilitation staff are able to break out of normative structures in order to create new SCI lifeworlds. Lastly, chapter seven uses “hope” as a concept to formulate how these three levels operate empirically and theoretically.

The distinction between primary and secondary is borrowed from Boas, who articulated a distinction between what he called secondary and primary explanations. Emotions are “cultural products” (Geertz 1973, 50), while affects are historically formed processes that are immanent to

spaces, events, images, memories, dreams, and all that with which anthropologists come into contact (Stewart 2007, 3). Emotions and moral values comprise secondary explanations which are rationalizations that result once something becomes a "subject of thought"—it is prone to being explained through a culturally salient logic (Boas 1940, 382). However, underlying these are primary explanations, which are historically predicated unconscious processes. For Boas, secondary explanations are often enforced through strong emotions, which reveal, for instance, what is in/appropriate.

Boas distinguishes between ritual and tradition using ‘primary’ and ‘secondary’. The ritual, which can be shared by many cultures, is often older than the tradition, which varies by culture, that rationalizes it and refers to it. The ritual is the primary and the tradition is secondary. The activity in process that we can track throughout history through something like a ritual is primary and our explicit rationalizations about them at a given point in time, such as why a tradition is practiced, are secondary.

It would be easy to liken this to a Kantian noumena or a Platonic Idea—where cultures may particularize a general form which is primary and therefore truer. However, secondary level rationalizations inhabit specific cultural worlds under politically negotiated languages and interpellations while primary level “affects...trace how the potency of forces lies in their immanence to things that are both flighty and hardwired, shifty and unsteady but palpable too” (Stewart 2007, 3). Such a nature of affects necessitates that we look to discourse and the ethnographic event to find its logics and affectivity.

For example, individuals may rationalize and re-interpret why we use forks to put food in our mouths rather than knives—because “one would easily cut the lips” one might rationalize—despite forks containing a significant amount of risk of injury as well (Boas 1911, 69).

Rationalizations often stem from force of habit, and we then seek to explain a practice in terms consistent with “the context of ideas in which it existed in the present” (Stocking 1966, 877). It is noteworthy that the third political level articulated above is mainly the lens through which ethical affects get translated into every day rational claims and statements.

For pwSCI, doctors and therapists have already determined whether they will be able to walk again. While it may be enticing to analyze such claims through relationships of power-over, this three-level approach would argue that prognoses are merely projections of medical knowledge onto patient conditions. As discussed above, the ASIA scale presents a neat, discrete assessment of injuries and bodily capabilities. It is relevant that very few pwSCI at the research site from which data in this dissertation are derived fit into a single category—a fact that physical therapists commonly accepted as contradicting their training. Seeing this in terms of dogma rather than right vs. wrong allows us to discern norms of thought driving these “situations of abandonment.” Indeed, “What we institutionalize in unemployment, in retirement, or in school, are controlled ‘situations of abandonment,’ for which the handicapped are the model” (Deleuze 2007, 235). Thus, what we express, and enable or dis-able from expression are doubly important.

The Role of Moral Anthropology

Didier Fassin (2012, 2) defines moral anthropology as a research concern which focuses not merely on “prescriptive” endeavors, but also “descriptive” ones that study “morals through issues, themes, regions of the world, and periods of history from a critical perspective.” This distinction between prescriptive values and descriptive norms forms a main distinction between the secondary and primary levels, respectively. This dissertation defines the primary level as both affective and ethical because “ethics”—“a life style, a way of thinking and living” (Foucault 2000, xiii), or a “practice rather than a vantage point” (Rabinow 1997, xix)—are normative,

developed temporally, and are often what is used to define the self-imposed “obligations” that comprise entire eras (Weber 2001, 19) and encompass an ontology.

Similarly, per Deleuzian repetition, an affect, each time it is expressed, changes according to its experiences and because of the expression itself—affects that we usually imagine must be singular. I define affects as a more intuitive, tacit phenomenon that is historical and thus temporal. Affects contain a history and provide a basis for who we believe we are and is where we often take for granted the role of culture in creating our subjecthood.

Much like Foucault’s work on the subject position focused on ethics, affect theory performs similar work. In contrast, emotions are those feelings that are more easily disconnected (albeit, only conceptually) from our sense of self, and which are more explicitly filtered through a culturally salient model (Lutz and White 1986; Laszczkowski 2019), much like morality. Emotions and morality lend themselves to prescriptive rationalizations. The work of moral anthropologists is relevant here as they commonly flatten the distinction between moral values and ethical norms, arguing that they are “hard to keep... apart in the actual flux of life” (Das 2012, 150; Fassin 2012; Mattingly 2014). However, distinguishing between norms and values (i.e., normative ethical self-creation and moral rationalities, respectively) is central to my theoretical framework.

Fassin (2015, 176) argues that the only two viable routes in moral anthropology involve examining social constraints imposed by a moral social order, and the individual dimension of ethics and freedom individuals have that allows them to decide for themselves how to live. These are points especially relevant to populations such as pwSCI that regularly experience discrimination. Ulla Berg and Ana Ramos-Zayas (2015, 665) argue that “racialized affect” tends to shape how minoritized populations are painted as more constrained by structures of

vulnerability while privileged and majority white populations are often granted more agency and empowerment in their own lives. Such an image of thought (an unquestioned orthodoxy) proposes a strong theory for the “weak” and a weak theory for the “strong” (Sedgwick 1997).

This dissertation uses Fassin’s definitions of morality and ethics above—of moral judgments as social values and ethical principles as normative processes—but departs from them by arguing that what makes ethical subjecthood (i.e., the subject we come to be because of our historical experience) necessitates an engagement with chronicity and temporality. Indeed, time is used as an ordering diagnostic tool while also often being what makes the difference in shifting subjecthood (Smith-Morris 2010, 22). Using the three-level approach described in this dissertation, norms are often tacit and reside within affective realities—something that applies to all cultural groups, not only minoritized or dominated ones. In other words, we all have worlds of experience that are driven by our engagement in the world not only emotionally, but as total feeling organisms whose very perspectives and experiences are shaped by our cultural histories (Quinn and Mageo 2013). Alternatively, moral judgments and values are often explicitly expressed and more easily objectified. Both exist in time, but morality is more prone to rationalization and tends to be explicitly, verbally, captured in ethnographic context. Tacit, unquestioned norms tend to be less so.

Fassin (2009, 37) argues that:

moral philosophy makes a constant effort to separate values and norms, the former referring to judgments as to what is right or wrong (or better or worse), and the latter referring to rules, principles, and obligations (or what to do or not do). In reality, if evaluative and prescriptive statements can be distinguished analytically, the distinction is much more difficult to establish empirically and is probably irrelevant because values arise at least in part from norms, and norms depend partially on values.

Like Fassin, James Laidlaw (2018) defines morality as social norms and constraints within society and ethics as a second-order reflection of these norms. Similarly, Jarrett Zigon (2017)

distinguishes between the two by identifying morality with unconscious norms and ethics with more conscious reflection and hence freedom. For all three, the morality comes before the ethical, where ethics is tied to freedom. The only major moral anthropological project deviating from these is developed by Veena Das (2012, 134), who has argued:

for a shift in perspective from thinking of ethics as made up of judgments we arrive at when we stand away from our ordinary practices to that of thinking of the ethical as a dimension of everyday life in which we are not aspiring to escape the ordinary but rather to descend into it as a way of becoming moral subjects ... through the cultivation of sensibilities within the everyday.

However, this anthropology of the everyday, which is crucial to anthropological work and theory, still largely accepts that moral judgments and values are only conceptually separable from ethical principles and norms.

However, I believe the Deleuzian/Foucauldian method described here offers a corrective. I'd primarily like to highlight the distinction in anthropological dialogues on ethics and morality as occurring between the social genealogy of moral judgment (related to culturally intelligible emotions) and the ontological reality of ethics (related to immanent affects). While morality and ethics are "hard to keep... apart in the actual flux of life" (Das 2012, 150; Fassin 2012; Mattingly 2014), affects and ethics are two ontological areas that have yet to be thought alongside one another.

Further, various anthropologists have written about how affects have a fundamentally political core (Ahmed 2004; Massumi 2015; Stewart 2007). For Ahmed (2004, 6), thought and evaluation happen at the same time something is felt by/in the body. This differentiates the bodily affect from the emotion, which results from this evaluative moral practice. To say ethical affects are "purer" is not quite right, as they are indeed affected by our cultural rationalities; but it is correct to say that emotions are rational world-creators, as the ontological weight of political

processes is already implicated within emotionality. If affects cannot be plausibly captured (as suggested by White 2017), then a three-level approach allows us to see those worlds in which affects are filtered and then implicated, as well as how indeterminate ethical affects (that were historically formed) come to be organized in very narrow yet rational ways.

What is the process that forms one's ethical affects, ending up in everyday rationalizations that stem from contemporary emotional and moral/logical reactions? Foucault (2008, 18) uses the phrase "regime of truth" to define not merely what we know and how we reference it (epistemology), but what can be known, what exists to be judged as true or false (ontology), and the process that "legislates" them as either true or false (politics). *I argue that this three-level approach gives us a way of structuring how we go from what we might call primary, historically predicated ethical affects towards secondary everyday moral rationalizations—through a legislative (political) structure.*

Power, Politics, and Identity: Intersectionality

Drawing on Foucault, I define power as an immanent force between actors. Rather than power presupposing a hierarchical relationship, Foucault (1994, 167) argues that "power relations" are a means of making ourselves intelligible; thus, rather than being "trapped," power is a means for pursuing possibility, change, and freedom. Indeed, much of disability activism describes situations as attempts to change one's relationships and contexts. Such a definition has clear links to anthropological theorizing that defines human behavior and experience as incapable of stepping out of its relationships, where "there is, there can be, no backstage" (Geertz 1973, 35).

Foucault's definition of power places power as immanent within human social life. I take Deleuze's assertion that "power is thus not what the will wants, but what wants in the will"

(Deleuze 2007, 205). Power is a fundamental element in the world—how we are made intelligible—rather than solely an object to be wielded and used to constrain others. Foucault (1997, 167) describes power relations as a way in which we find our freedom for the fact that, while “the struggle, of course, is not symmetrical...it means that we always have possibilities, there are always possibilities of changing the situation.” Thus, rather than trapped by power, we are instead interpellated, made intelligible, and differentially in/capable through our relationalities—which are far from centralized (they are diffuse) nor wholly repressive (they define the terms of our potential freedom).

This consideration of how we become intelligible is important to another concept I rely on: intersectionality. Intersectionality arose out of critical race theory (CRT), which radically moved to interrogate race as an important facet of understanding the manifestation of differential treatment under the law (Carbado & Harris 2019, 2214). Like the rest of the theoretical paradigms here, intersectionality is a fundamental rejection of a doxical identity. Rather than additively treating identity markers of marginalization as compounding marginalization through a cumulative model, intersectionality pushes for a questioning of identity as such, defrosting concepts to understand how social structures, such as the law, serve to render the experiences of certain groups invisible (Crenshaw 1989).

In her seminal article on the matter, Kimberlé Crenshaw (1989, 142) describes how Black women’s experiences of discrimination are obscured by the unique ways in which this particular form of racialized sexism (or, sexualized racism) is expressed, being rendered invisible, with Black women’s abilities to seek recourse for discrimination limited by the unwillingness of the US legal system to recognize Black women as a unique protected class in itself rather than an amalgamation of two separate classes (i.e., *White women* and *Black men*). Intersectionality thus

questions identities as natural, straightforward categories. However, as discussed above, it is prone to being simplified in flat terms that make an “oppression Olympics” interpretation more likely due to its being situated in an identitarian-oriented image of thought.

However, intersectionality points to how (1) social constructs (especially policy-inscribed ones) do not adequately account for the experiences of marginalized populations in an additive or linear way, and (2) how a discriminatory doxa serves to limit the opportunities of people of certain identities in differential and often unexpected ways. This latter point is taken up by anthropologists such as Khiara Bridges (2018) who has explored how Black women are differentially deemed “[un]fit for social participation” resulting in loss of privacy rights (Bridges 2017, 11) and are often the subject of stereotypes and prejudices by medical practitioners (Bridges 2011, 136).

Intersectionality articulates minoritization as an ongoing process. Identities are relational processes and not things that exist in themselves. They are created, reified, through things like stereotypes, and other symbolic practices that communicate a certain metaphysics of a given identity. However, an intersectional approach helps reveal minoritization as a problematization: who is minoritized, with respect to whom, in what situations, and in what situated forms?

Intersectionality, and its critique of identity, is especially salient for pwSCI and people with disabilities more broadly, who are often thought of as regular people minus ability—resulting in the perceived normative need for a cure (as articulated in Donovan 2007 and Lifshutz & Colohan 2004) or at least pushing for structural inclusion in such a manner that normalizes socioeconomic productivity as the primary form of societal participation (Mitchell & Snyder 2015). Indeed, Mitchell and Snyder (2015, 4) in their *Biopolitics of Disability* describe how neoliberalism utilizes identity categories as potential consumers and offers individuals few

spaces from which to recognize themselves outside of market preferred values, needs, and desires. Disabled people must conform to market requirements and standards. In either case, *disability* is constructed in relation to *ability* as an originary or default form, necessitating an intersectional analysis. These considerations have necessitated a methodological focus on the everyday as a site of analysis—a focus with which anthropology is adept.

These two lessons from Deleuze (the repetition in how we render ourselves unconscious and how there are no conceptual identities) and Crenshaw (the failures of intelligibility that affect certain minoritized populations, failing to account for their experiences) necessitate a robust theory of a social unconscious that is legislated through (using Foucauldian terminology) governmental rationalities. It is an inherently political process that guides us towards discounting elements that might institute change and difference. Identity is thus political not only because they are situated, negotiated, and in flux, but because identity categories are processually and differentially in/capable of being seen and integrated into normative structures.

What then are the regimes of truth that leave affects to be narrowly understood, defined, or even felt in human daily life? I argue that such politics of filtering “truth” should be thought as inherently ontological. Ontopolitical, in the sense in which “problems are framed, bodies are shaped, and lives are pushed and pulled into one shape or another” (Moi 2002, viii).

At its core, intersectionality helps us understand how systems construct their terms in ways that make them seem like neat, natural categories. However, categories like “Black,” “woman,” or “disabled” merely point to gaps that may exist within a system because it wants to “turn names into things” (Wolf 2010, 3). Geertz (1973, 18) warned about the dangers of seeking “impeccable depictions” as “there is nothing so coherent as a paranoid’s delusion or a swindler’s story.” Indeed, while much of ethnography and anthropological theory-making is a construction,

we typically argue that they are convenient ones. Theoretical turns such as intersectionality help reveal where such depictions may fall short.

The Three-Level Approach: A Brief Example

In explaining how we currently reside in a neoliberal governmentality, Foucault (2008, 252) argues, amongst other things, that “The subject is considered only as *homo oeconomicus*, which does not mean that the whole subject is considered as *homo oeconomicus*.” In other words, understanding humans as economic subjects, and even ones where corporations and people are synonymous (Citizens United v. FEC), is the rationality in which humans are embedded. One which results in the neoliberal cultural prescription that a person must never relinquish his or her personal interest (Foucault 2008, 275). This helps contextualize Mitchell and Snyder’s (2015) biopolitical project—disabled people cannot extricate themselves from this system, but they can still create new norms within it.

Nevertheless, such a rationality could only have been established by first traversing through a laissez-faire system that firmly established “Europe” itself as an economic region. As an example, this perspective may partially explain the impetus for NATO to intervene on behalf of Ukraine, whose population was seen as more white, European, and thus, “look like us” (Bayoumi 2022). The discomfort of seeing Europeans bombarded and fleeing their homes takes on a totally different bodily feeling and rationalization, which stems from a historically predicated global stance where “[t]he game is in Europe, but the stake is the world” (Foucault 2008, 56). Situations that violate this dogma are simply intolerable.

The three levels imply that moral judgments and their emotional and rational expressions (rational secondary), a legislative and reality-forging power (ontopolitical tertiary), and a guiding ethical affect (unconscious ethical primary) are each immanent in the everyday and thus

present in the ethnographic context. However, while “emotions” can be rationalized in such a form to enforce a cultural prescription—such as in Boas’ example of a child causing “displeasure” in his parents by smacking his lips while eating (Boas 1911, 68-69)—the historical development of a cultural form often stands apart from these emotional reactions. What this at least implies is a fact that our emotions as such—such as disgust, pleasure, or modesty—are embedded in cultural worlds that filter the more active ethical affective processes from which they were derived. In the Ukrainian example above, rather than reactions to Russian atrocities in Ukraine being somehow “worthy,” what may be more insightful would be the series of rationalizations that prevent these same European news outlets from inciting outrage at the atrocities being committed elsewhere such as in Palestine or Iraq. There exist invisibilizing rationalizations that create a particular unconsciousness.

“A good interpretation of anything—a poem, a person, a history, a ritual, an institution, a society—takes us into the heart of that of which it is the interpretation” (Geertz 1973, 18). Thus, my stance throughout this dissertation is one of “critique”—which does not mean being contrarian, but instead attempting to illuminate that heart. The underlying ethic.

Foucault (2007, 47) defines *critique* as an act that desubjugates the subject “in the context of... the politics of truth.” He critiques “truth” and its limits as a dogma with a given set of rules and procedures through which techniques are used to enforce and reinforce a certain orthodoxy. “Truth” itself becomes a regime that makes this or that utterance or rational explanation possible. Truth is guided by a given affect that is—and this is where Foucault and Boas might agree—historically predicated. Foucault echoes this when he describes a “grid”—which is “a system the rules of which permit the creation of new knowledge”—as stacked atop older ones, forming a historical continuity (Chomsky and Foucault 2006, 132).

This dissertation argues for theorizing that looks at those things often considered extraneous data, defining them as a necessary part of the event and how ethics/affects, rationality, and ontology become co-constituted. Given this, I use Deleuze’s description of the institution as “procedures of satisfaction” where human tendencies (emotional, social, or pragmatic ones) are satisfied, but upon which they do not rely (Deleuze 2003, 20). In other words, human subjectivity can find its fullest expression in an institution—for instance, where “brutality discovers in war its best means” (ibid.)—but there is still a space between the rationalization and its satisfaction. If institutions are mere expressions, then what do they express? I answer: an affect underlying an ethical practice, where people may enact their own kinds of power.

Chapter Three: Research Methods

This dissertation focuses on the dynamic relationship between subjectivity (emotions, thoughts, and affects) and the various intersubjective networks (such as rehabilitation centers as well as social and familial relationships) that pwSCI inhabit. Thus, two forms of triangulation (Merriam and Tisdell 2016) were used: (1) methodological triangulation, in which I investigated SCI experience, care, and rehabilitation through the use of participant observation and various forms of interviewing, and (2) data triangulation, where I collected ethnographic and interview data from the same interlocutors multiple times throughout the project sampled from a variety of pwSCI, their caretakers, and rehabilitation administrators. In this chapter, I review the methods I used as well as a rationale for their inclusion in this project. However, first I will discuss issues concerning methodological inclusion that must be necessarily negotiated in an ethnography of disability conducted by an able-bodied anthropologist.

Research Site Background

I conducted research at the rehabilitation site that I call Keep Performing (KP) for about 10 months, from the beginning of September 2021 to the end of June 2022. KP first opened in 2015 and was started by a veteran who was injured in 2008 while serving in the military in Afghanistan, and who was dissatisfied with the kind of rehabilitation methods offered by the local Veteran's Affairs Hospital – which had already defined him as beyond being able to recover motor or sensory function. KP is an activity-based therapy (ABT) center in Central Florida. ABTs have been defined as “interventions that provide activation of the neuromuscular

system below the level of lesion with the goal of retraining the nervous system to recover a specific motor task” (Behrman & Harkema 2007, 185). ABT thus focuses on systematizing neuroplastic processes to promote recovery for long-term, chronic patients (Kaiser et al. 2020). ABT facilities use equipment and exercises that challenge patients to utilize whatever functional capabilities are present, no matter how minimal they might be. They also assist in promoting movements of the body that clients may have no functional control of, nor sensory feedback for.

KP’s founder, in collaboration with his wife, first attended rehabilitation at a facility one and a half hours away, going three days a week. After two years of this strenuous schedule, they decided to seriously consider starting an ABT facility of their own. KP started by serving only a handful of veteran clients who were similarly dissatisfied with the VA Hospital’s rehabilitation methods, which include 45-minute sessions with about 30 minutes of that allotted time dedicated to actual rehabilitation exercises that never take the patient out of their chairs. KP began with the help of only three staff members but has since grown to serve over 55 unique clients per month with the help of 12 staff members—one physical therapist, two physical therapist assistants, one lead trainer, three trainers, and five training aides. All staff members except for the training aides can lead sessions with clients and patients.

The terminology separating ‘clients’ and ‘patients’ exists for very good bureaucratic reasons. KP divides its staff into two care groups: physical therapists and trainers. Physical therapists care for those whose insurance, mainly Medicare, pays for their rehabilitation sessions.² KP also offers a self-pay option where those who would like to receive their services,

² KP qualified for Medicare in 2019, about 3 years after opening. This involves a process of Medicare negotiating how much it will pay for sessions, which for most services tends to be less than institutions like the VA would/do charge patients. This is relevant as Medicare pays between \$138-\$168 per session—this is doled out through units where one session can be billed for as much as 6 units. This is a process that involves Current Procedural Terminology (CPT) codes for outpatient therapy. As a rule, one unit can last anywhere from 8-22 minutes. Institutions like KP must strategize sessions not only based on patient healing and therapy goals, but also based on what will be billable to Medicare and other insurance options (of which there are few).

but whose insurance does not pay for it (which are most private insurances as well as Medicaid), can still reap the benefits of this kind of therapy modality. Trainers lead sessions for these individuals.

Relevantly, this dichotomy is reflected in the organization's language. KP staff refer to those whose sessions are covered by insurance, and who are thus treated by physical therapy staff, as "patients." It refers to those who self-pay, and thus treated by trainers, as "clients." Clients can receive modest discounts depending on how many sessions they attend. For instance, if they attend 7-10 sessions per month, they will receive a 25% discount. At 17-20 sessions per month, a 50% discount. Thus, clients may pay anywhere between \$180.00 to \$90.00 per 2-hour visit, respectively, each of which amounts to about one and a half hour sessions.³ This is significantly longer than what is offered by the VA and the other major hospital nearby.

On the other hand, those whose Medicare covers their visits must dedicate about one entire session per month to assessing their progress, where the physical therapist and a patient's primary care physician (PCP) must provide a justification for why patients should continue to receive care at KP. As will be further developed in the data sections of this dissertation, Chapters 4 through 6, patients develop concerns in navigating their care with their PCPs and insurance while clients develop concerns with how progress is tracked. Nevertheless, these dynamics structure the relationships developed between staff members and patients/clients. This is the social context in which I entered as a researcher at KP.

³ It is relevant that the amount that Medicare pays for its patients is at the midpoint between the minimum of \$90 and the maximum of \$180 that self-pay clients can pay. While this seems to penalize those who can attend sessions less often, the accountant at KP explained to me that any client can claim 20 sessions and be billed at the reduced rate, and they will not get penalized for attending less than 17 sessions. A loophole exists in KP's billing. However, in follow-up conversations, not many clients seem to know about it, and even seemed reticent about the thought of taking advantage of such a loophole.

Positionality

My motivation for carrying out this research is as important as how my ability separates me from my various interlocutors with paralysis. There were many instances where I shared with interlocutors the basis of my research. My brother has a very high-level SCI – an injury at his cervical level 1 and 2 – which makes him ventilator dependent, and which would also (as I would come to find through the process of this research) likely disqualify him from attending a rehabilitation facility such as KP. As my brother’s primary caretaker, I became privy to the many health concerns, demands, and symptoms associated with pwSCI and the many secondary conditions they may experience. Undoubtedly, this experience is quite personal and makes me both sensitive to these issues as well as not wholly separate from them.

Additionally, as an able-bodied man, I am granted the privilege of being able to communicate, express myself, and be-in-the-world in a way that is often more intelligible and effective within a fairly ableist world. Drawing on Foucault (1997, 164), I define power as a field of intelligibility, where we are given an ability to struggle; to be recognized by authoritative mechanisms; and granted a plethora of possibilities. In such a framework, privilege is merely a function of how intelligible or not intelligible a given relational power defines one’s position. Relatedly, norms are an expression of the degree of one’s intelligibility.

Taken together, conformity to a set of norms brings with it some set of privileges, and one’s embodied in/capability of conforming to such norms modifies the extent to which one may be rendered in/capable. In other words, “identity” refers to a social category that carries much tangible social weight as a function of the effects that it produces – e.g., ‘privilege’ or ‘oppression.’ While ableism is defined as something that is inherent within a system, this

theoretical perspective defines ableism as what is produced by a system's very mechanisms. Analogous to structural racism, in the absence of bad actors, ableism would and does still exist.

For example, navigating my research site at KP brought about many instances where therapists and staff there would refer to clients and patients in somewhat disparaging ways – such as one instance where a physical therapy assistant (PTA) laughed while explaining how one of the patients there, Tom, who is a 30-year-old veteran injured for eleven years, tried to carry a conversation with her despite his traumatic brain injury (TBI) making it difficult for him to do so, at least in a timely manner expected by this PTA. While it may be easy to moralize this kind of statement as one where this PTA was harsh or lacking manners, I believe there is a more nuanced discussion to be had about how discomfort (an affective reaction) manifests within various social environments. This will be fleshed out further in Chapter 6, where I discuss the role that joking may play within such a context where debilitated bodies are both on display while also being scrutinized for their abilities, or lack thereof.

Basic SCI Terminology and Etiology

SCI is characterized by paralysis that is brought about by lesions or injuries to the spinal cord or its surrounding structures. This brings about varying degrees of impairment in physical functioning. It has been estimated that about 54 in every one-million people in the US suffer SCI each year—this is roughly 17,730 cases of SCI annually (Jain et al., 2015). However, it is noteworthy that the current, ongoing COVID-19 pandemic has resulted in decreased trauma admissions, such as an 85 percent decrease of motor vehicle collisions, at an unprecedented level largely due to social distancing measures and decreased travel (Kamine et al., 2020). This is especially important considering that in a typical year in the US, SCIs are caused primarily by unintentional falls (40.4%), car crashes (31.0%), and firearm injuries (5.4%). However, these are

also more or less common by age group. For instance, those 65 and older experience more falls (66%), those 16-24 years of age experience more firearm injuries (18%), and young adults (ages 16 to 24) and middle-aged adults (ages 25 to 44) both experience high rates of motor vehicle accidents (44% and 40% respectively) (Jain et al. 2015).

Roughly half of those with SCI experience complete sensorimotor impairment below their lesion level (Dobkin, 2003). Furthermore, bladder and kidney infections, bowel issues, pressure ulcers, increased risks of diabetes and obesity, and respiratory complications are the major secondary conditions that those with SCI experience (Burns et al. 2013). In one study (n=150), higher injury levels (such as quadriplegia) have been shown to greatly influence the onset and presence of secondary conditions (New 2016). Considering that secondary conditions seriously impact life satisfaction and quality of life (Piatt et al. 2016), as well as that SCI is highly variable with patients suffering from varying degrees of impairment, diverse experiences characterize this group of trauma survivors.

The spinal cord is about 45 cm in length, enclosed within the vertebral column which extends from the brain stem all the way to the first lumbar level (L1), making the actual spinal cord shorter than the vertebral column. The spinal cord is divided into four regions: cervical (C1 through C8), thoracic (T1 through T12), lumbar (L1 through L5), and sacral (S1 through S5). Throughout this dissertation, I mention patients and clients, as well as their injury levels. This is consequential as injury level is generally associated with certain physical limitations (Figure 3).

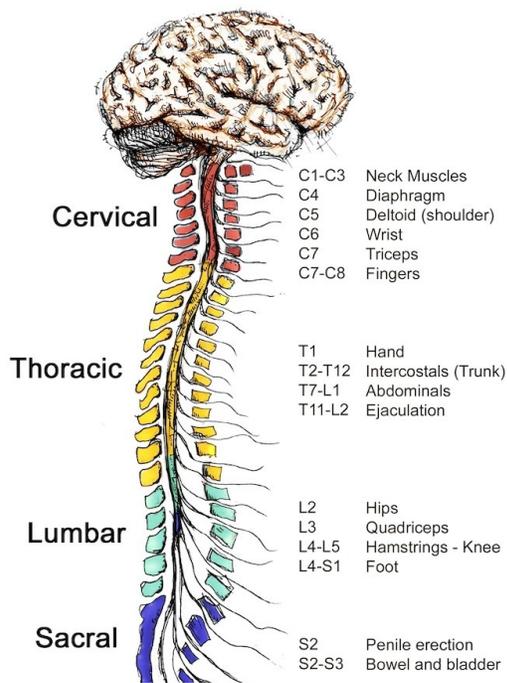


Figure 3. Spinal cord with associated functions. From: <https://www.christopherreeve.org/living-with-paralysis/health/how-the-spinal-cord-works>

Symptoms of spinal cord injury vary greatly, depending on how it is affected by lesions, and whether the lesions exist in dorsal, lateral, or ventral regions along motor or sensory pathways (Rossignol 2013). For example, a damaged L1 vertebra can result in conus medullaris syndrome characterized by sphincter paralysis, dysfunction of the bladder, and perianal anesthesia. Depending on the injury level, a person can lose the use or sensation of their legs (paraplegia), or they can have their arms and neck affected

(quadriplegia). Paraplegia is associated with injuries or lesions starting at the T1 vertebrae of the spine while the cervical vertebrae (C1-C8) are associated with quadriplegia (Silva et al., 2014).

With a high enough injury (starting at the C2 cervical vertebrae), individuals may lose the ability to breathe on their own, necessitating the use of a ventilator. Most SCIs (about 55%) occur at the cervical level (C1 to C7) while about 15 percent occur at the thoracic (T1-T11), thoracolumbar (T11-T12 to L1-L2), and lumbosacral (L2-S5) regions (Austin, Rowland, & Fehlings, 2013). The extent to which the spinal cord may be affected varies. For instance, it may be sheared, stretched, compressed, and is very rarely ever transected during injury, even in cases involving severe neurological deficit—laceration of the spinal cord has been observed to occur due to vertebral bone fragments or from the use of weapons. Extent of damage also modifies

how SCI manifests in patients. Thus, in the following chapters, this tends to create high degrees of variability, even between patients who, per their diagnosis, might have similar injuries with different manifestations.

Motor impairment with SCI occurs due to damage to both upper and lower motor neurons, causing paralysis of muscles at and below the level of injury. Similarly, sensory information (carrying pain and temperature information) is disrupted with damage to first and second order spinothalamic neurons and axons. A complete injury means that there exists no motor or sensory function below the level of injury while an incomplete injury means that there is at least partial motor or sensory function (Palimaru et al. 2017; Teufack, Harrop, & Sharan, 2013). The American Spinal Injury Association (ASIA) Impairment Scale is a comprehensive guide used by clinicians in assessing the completeness of lesions for those with SCI and has been greatly beneficial for classifying injury types. Evaluations of impairment after SCI include considerations of both injury level (at specific vertebral levels) as well as the extent to which sensory or motor functions have been affected. The grades are:

- A Complete: No motor or sensory function is preserved below the neurological level of injury (NLI).
- B Incomplete: Sensory but no motor function is preserved below the NLI.
- C Incomplete: Motor function is preserved below the NLI, but more than half of the key muscles below the NLI have a muscle grade less than 3.
- D Incomplete: At least half of the muscles below the NLI have a muscle grade > 3 .
- E Incomplete: No sensory or motor deficits (this grade is only used to track recovery in patients with previous deficits). (Kirshblum et al. 2011).

Throughout this dissertation, I use terms such as “patient,” “client,” and “rehab participant” to refer to pwSCI presented here. As further discussed in Chapter 4, “patient” refers to those who receive treatment by licensed physical therapists, and “client” refers to those receiving treatment from unlicensed trainers, who went through no formal rehabilitation training in order to perform their work. I use “rehab participant” to refer to both patients and clients who attend rehabilitation sessions at Keep Performing, the rehabilitation center from which I collected 10 months of ethnographic data. In addition, to refer to pwSCI dis/ability, I mostly use the term “debility” in order to situate my focus on the limitation in a person’s physical functioning. I follow Jasbir Puar (2017), who I reference in chapter one vis-à-vis how “debilitation” bridges the abled-disabled dichotomy by focusing on the contested nature of debilitation with regard to accessing disability rights. As “disability” is a more contentious term, with its meaning also denoting how social structures do not adequately attend to certain debilitated bodies, I choose “debility” instead.

Methodological Inclusion in Ableist Anthropology

Regarding ableism, there are two important considerations I took during this research. The first is analyzing how ableism is a manifestation of normativity. For instance, Kasnitz and Shuttleworth (2001, 20) argue that disability is often defined by those who are abled and thus, those who are labeled as *disabled* are such because they “experience discrimination on the basis of perceived functional limitations.” In other words, the very population with privilege is the one defining those without it. This helps contextualize social relabeling as a process of conforming to a dominant norm (Waxler 2016). The kind of revision of identity performed through illness narratives that Hunt (2016) describes is about resolving social difficulties that manifest through an illness narrative by meeting a normative expectation. The result is reifying ableism. One

definition of what is normal renders some individuals invisible or oppressed (which amounts to the same thing).

Secondly, ableism may be seen as a product of how this normativity becomes justified, thus obscuring its core mechanisms. Rather than finding the answer in actors' intentions, or in using the correct research methodologies, this point focuses on how our rationalizations render invisible/clothe some core mechanisms. For instance, autoethnographic methods have been laudable particularly because they center the voices of people experiencing disability and debility while positioning them as explicitly co-constructors of their own discourse. Per Kasnitz (2020), these methods provide an opportunity to regain one's 'self' in a constructive and active, rather than passive, way.

This is one powerful method for upending the presupposed passivity of disabled persons. However, ableism still plagues anthropology, where "as a discipline we are missing a deeper understanding and have not yet operationalized our knowledge to make a more accessible profession" (Kasnitz 2020, S24). Indeed, traditional ethnographic methods themselves are not inherently ableist, but social structures and one's positionality can be. How is it possible that even methodologies meant to be inclusionary may fall short of inclusivity? This dissertation does not use autoethnography, but it does seek to question how anthropologists must conduct disability anthropology – which allows disability scholarship to influence our theories, methods, and thinking (Hartblay 2020).

I draw on Olúfẹmi Táíwò's (2021) notion of "being-in-the-room privilege," where he argues that we often focus on actors in the room – such as in academia, where diversity trainings force white people in a room to defer the floor and attention to people of color – while ignoring how the room itself is structured in such a way that it prevents certain people (i.e., those most in

need of having their voices uplifted) from entering the room in the first place. Most relevantly to the point, Táíwò highlights how abdicating responsibility to those who have suffered “asks something of trauma that it cannot give” and only serves to increase burdens on those who have suffered rather than lifting it (Táíwò 2021).

Thus, on the one hand, a core critique here is of how we structure difference, which reiterates much of the discussions of the previous chapter. We often create a commonsense conception of difference where we assume that a person of a given background must have had a quintessential experience of disadvantage and oppression, owing to their racial or ethnic identity. This over-identifies one’s identity and social location with how others assume what one’s experience must have been. On the other hand, such practices only serve to abdicate responsibility, ensuring that the concerns of the sufferer remain in his/her care. This over-emphasizes ownership of trauma. ‘Ownership’ collapses experience (‘my’ trauma) and responsibility (‘I’ must do the work).

Regarding disability, it could be easy to practice such cosmetic solutions, such as altering language used, or by placing the onus on those with disabilities directly. However, this would only serve to reinforce those norms currently obstructing the lives of those with disability, as it would not create the kind of coalition conducive to real change. Language is clearly an important facet of how communities and groups come to be interpellated (Butler 2007). However, how responsibility gets distributed (i.e., how we *come* to repair) is more important than *performing* reparations.

Puar (2017, 20-21) illustrates how claiming disability rights also functions within a sociopolitical sphere that simultaneously racializes, privileges, and commodifies bodies and disability itself while letting academics “off the hook.” All this simultaneously functions within

structures that create debility without granting all those culturally defined as debilitated with disability rights. Thus, we must understand disability within this discursive and material sphere. These considerations spur the direction of this dissertation, where I attempt to insert myself within privileged spaces, acknowledging this privilege rather than attempting to narratively (i.e., cosmetically) minimize it.

Campbell (2001, 44) defines ableism as:

a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human.

A recent volume on *Ableism in Academia* positions participatory frameworks as most conducive to inclusion and participant engagement (Brown and Leigh 2020). In this spirit, drawing largely on anthropological qualitative methods and theory, Berger and Lorenz (2015, 4) refer to this kind of research as *emancipatory research*, which “posits that research about disabilities should be undertaken in collaboration with people with disabilities and designed and applied in ways that advance the personal, social, and political liberation of this constituency.”

My research uses reflexivity as it is an important approach attempting to provide such emancipatory. Reflexivity is a crucial aspect of research where researcher positionality, bias, beliefs, and subjectivity are integrated into the research process (Merriam and Tisdell 2016). Indeed, given my theoretical perspective, this research inevitably involved my ability to distinguish my own biases and norms in order to fully flesh out how they interacted with and confounded those of my interlocutors. I kept a journal throughout the ten months of data collection, noting impressions, emotional reactions, and rambling thoughts that came up after my experiences at KP.

Given the sensitive nature of this topic, as well as my personal experiences interacting with SCI through my time as a caretaker for my brother with SCI, along with the methods outlined below, keeping my own journal helped me to constantly negotiate my own feelings, biases, and thoughts that arose throughout this research. My decision to collect in-depth, experience-near narrative data is informed by the strength and depth of these methods along with an ability for elaboration and correction throughout the research process (Berger and Lorenz 2015). Given all these considerations, my research centers an analysis of understanding the contested process of debility through bodies legally, medically, and socially deemed disabled (Puar 2017).

Overview of Methods

The following methods are placed within a framework drawing on several qualitative research paradigms. I used the constant comparative method often associated with grounded theory, where new data are compared in an ongoing fashion to data already collected, thereby grouping data through a continuous process of coding, theme-ing, and data organization (Charmaz 2014). This aligns with a framework articulated within narrative inquiry (Kim 2016, 64), in which we may center “rhizomatic relationships” to highlight multiplicity and circularity rather than linear and dichotomous relations. In other words, we must understand the multitude (not only bidirectionality, but multidirectionality) of relationships between different types of data. For example, the medical anthropological literature on disability and pain has captured narratives of suffering and helplessness (Good 1993; Kleinman 1988; Murphy 1987), but also of resistance, fighting back, and how people create habitable worlds for themselves (C. Bailey 2019; Bloom 2019; Drolsbaugh 2008).

A synthesis of the literature shows the multiplicity of perspectives and opinions in the macro, such as through theorizing about political economic processes, but this multiplicity has not been thoroughly teased out in the micro. This means understanding the kinds of affects and personal dimensions involved through analyzing cognitive and relational experiences. Laura Nader's (1972) "studying up, down, and sideways" approach is one way of allowing one set of data to contextualize others. Not only do we study power structures and their subjects, but we also must place these data into relational context. I believe that this approach helps contextualize how 'rhizomatic' relationships in narrative methodologies are conceptualized—as vertical or horizontal, which, "unlike trees or their roots... connects any point to any other point" at various scales (i.e., local, organizational, global, etc.; Deleuze and Guattari 2020, 21).

For methodological guidance, this dissertation was guided by the following research questions:

1. How does the SCI apparatus function?
2. How does care and caregiving reinforce and challenge normative ableism?
3. How do people experience SCI emotionally and psychologically?

These questions link to the kinds of methods used, where I investigate the structure of rehabilitation at KP; interviewed both rehabilitation participants and some of their caregivers; and used in-depth interview methods to investigate the emotional and psychological worlds of pwSCI. However, the research process starts with how I selected participants on which to focus.

Sampling and Recruitment

A total of 44 individuals were interviewed a total of 58 times during this research (Table 1). The four main subgroups of participants were pwSCI (n=15), rehabilitation staff (n=20), caregivers (n=7), and SCI advocates (n=2). Analyzing these data in tandem with one another

gave valuable insight that otherwise might have been lost had I focused on one single interlocutor group. For instance, the experiences of pwSCI are constantly being evaluated (e.g., “what should you be doing?”), assessed (e.g., “how well are you doing it?”), and modified (e.g., “how can we make it better?”) by rehabilitation staff, caregivers, and advocates. This results in moral exercises and conundrums that were being felt, expressed, and enacted during this project. All participants except for pwSCI were gained through snowball sampling – which draws on extensive networks of friends and colleagues that may exist at a research site (Guest 2015, 236). Staff, caregivers, and advocates were selected based on their role in the lives of pwSCI as well as their engagement and familiarity with KP.

Table 1. Summary List of Participant Types.

Participant Types	Total Participants	Number of Interviews
PwSCI	15	25
KP Staff	20	24
Physical Therapists	4	5
Trainers	4	5
Training Aides	5	7
Interns	2	2
Operations Managers	2	2
Accountant	1	1
Director	1	1
Caregivers	7	7
SCI Advocates	2	2
Total	44	58

PwSCI Participants

Maximum variation sampling – where participants are selected based on several dimensions of interest – was used for pwSCI, who were approached through participant observation activities and invited to participate in subsequent interviews, including semi-structured interviewing and experience-near approaches (Guest 2015, 236). These dimensions of

interest included gender, age, injury level, and length of time since injury (Fekete et al. 2013; Kirshblum et al. 2013). All pwSCI interview participants are listed in Table 2.

Table 2. PwSCI Participant Demographics.

Pseudonym	Age	Race- Ethnicity	Gender	Injury Level	Number of Years Injured	Number of Interviews	Interviews	
							SS*	EN**
1. Jamie	26	Black	F	C7	6	3	1	2
2. Kevin	64	white	M	C4-C5	11	2	1	1
3. Jessica	40	white	F	C6	4	4	1	3
4. Tom	30	white	M	T4 + TBI	11	3	1	2
5. Clancy	40	white	M	T12	2	1	1	0
6. Helen	65	white	F	C-level	2	1	1	0
7. James	50	Black	M	C6-C7	28	2	1	1
8. Karen	65	white	F	T10	2	1	1	0
9. Caleb	23	mixed	M	C5	1	1	1	1***
10. Lauren	42	white	F	TBI	6	1	1	1***
11. Sam	56	white	M	L1	2	1	1	0
12. Paul	21	white	M	T5-T6	4	1	1	1***
13. Beatriz	22	Hispanic	F	T10	2	1	1	0
14. Warren	30	white	M	C3-C4	10	1	1	1***
15. Matt	50	white	M	C5-C6	5	2	1	1
Mean (SD)	41.6 (16.07)				6.4 (6.87)	1.6 (0.83)		
*Semi-structured interviews							15	14
**Experience-near interviews								
***semi-structured and experience-near interviews conducted in the same interview session					Total interviews	25		

As a qualitative ethnographic study, I sought to understand the depth of experience in individuals and families sharing similar and different injuries and physical functioning. Based on the insights they offered for analysis, using all research methods below, I approached pwSCI who experienced paraplegia and quadriplegia. As I learned during my research, selecting a participant on a ventilator was not possible, as no patients or clients used one. A total of fifteen

of these interlocutors participated in these interviews. Interviews on average lasted 1.5 hours (Range=15 minutes to 2 hours and 26 minutes; SD=0.67). Variation existed in the number of interviews performed because some participants were either more succinct than others, or in the case of one, less willing to share any specific information about his illness experiences.

Nevertheless, all participants were engaged multiple times during the research period. For instance, I had several unstructured conversations with every one of these participants. In addition, with interviews lasting on average 1.5 hours, the level and engagement and rapport established, as well as the depth of conversational topics (for instance, touching on injury, support networks, and daily experiences with SCI) all signal how entrenched within this community I became. Often in the midst of an interview, participants would ask me about my own experiences with SCI, where I would readily share some of my experiences as my brother's caretaker. In short, relationships with participants (and therefore data collection) surpassed the interview session.

These SCI demographic categories indicated in Table 2 were selected for the medical designations that often exist between categories, which help modify what many pwSCI experience (Kirshblum et al. 2011). PwSCI were screened for the following eligibility criteria: at least 18 years old; resident of Central Florida; has a diagnosed SCI (although one TBI participant is included in this research); and has participated in rehabilitation activities at KP. PwSCI participants were interviewed in their homes (n=2) or through the Zoom video conferencing software (n=13). All other participants and participant types were interviewed face-to-face on site at KP.

Methods

In this research, three primary methods were used to collect data: participant observation, semi-structured interviewing, and experience-near interviewing. Two additional methods were attempted: epidemiological surveying and participant dream journaling. The survey will be discussed as it relates to those participants interviewed; however, because the appropriate statistical power was not achieved, results cannot speak beyond how it supplemented interviews. Journaling will not be described here, as many of my interlocutors reported no longer having any dreams after their injuries; thus, participant journaling emerged as less possible for this population. However, this latter emergence points to the many transformations that may occur after a significant alteration to one's neurological system.

Participant observation

For this project, participant observation was the primary method for data collection as it entails building trust with interlocutors to permit access into daily experiences and activities. Indeed, participant observation has been conceptualized as a starting point in anthropological inquiry (Schensul and LeCompte 2013). However, it is also one of the few ways in which culture as both tacit and explicit may be captured, negotiated, and analyzed (Musante 2015). It is also a means of embedding continuous assessments of research assumptions and findings throughout a study. Most importantly, the theoretical model described in Chapter 2 presumes that the various symbols (linguistic or otherwise) being exchanged in a social discourse links to an underlying community ethic that researchers are capable of interpreting (Geertz 1973, 18).

Participant observation occurred over a period of about ten months primarily in a rehabilitation setting and occasionally in people's homes. I interacted with pwSCI regularly by observing physical therapy and rehabilitation sessions, participating in community events and

recreational activities occurring primarily in person. While COVID-19 was an initial concern, many of the precautions in place at KP were lifted after the fourth month of data collection (around January 2022).

Epidemiological survey

A survey was created based on various instruments that have been specifically validated for pwSCI. Various health issues such as obesity, chronic pain experience, mental health (including depression and anxiety), and social well-being (through quality of life and satisfaction with life scales) measures were combined with considerations of cognitive appraisals and adverse childhood experience indicators in order to flesh out their associations with food insecurity, sociality, physical functioning, and mental health levels—which research has found to all generally be positively correlated (Brown, Ciciurkaite, and Imlay 2020; Cook et al. 2017; Diener et al. 1985; Jang et al. 2004; Jörgensen et al. 2017; Mignogna et al. 2015; Schüssler-Fiorenza Rose et al. 2016).

In addition, while adverse childhood experiences (ACE) and food insecurity have been investigated in people with disabilities broadly (Schüssler-Fiorenza Rose et al. 2016), few studies have looked specifically at pwSCI. Relevant sociodemographic measures were also included. Data collected (n=13) helps contextualize participants' experiences of adverse childhood experiences (ACEs), post-traumatic stress, social well-being, chronic pain, physical functioning, and cognitive appraisal levels.

Experience-near Methods

Within phenomenological anthropological theorizing, Csordas (1993, 135) positions the body as a “subject that is necessary to be” in experience-near approaches. For instance,

experiences (such as pain) that defy articulation (Kleinman 1988; Throop 2010) are often presented as pre-reflective and “world-destroying,” stuck at the brink of language (Good 1993, 121). However, pain can also come to be articulated as meaningful and often morally valanced, ceasing to be mere suffering (Throop 2010). This given (immediate and unreflected) experience thus resides in tension with the ability to attribute meaning (the meaning-given; Throop 2009). Experience-near phenomenological methods posit that experience begins with a subject and ends in objects—whether those objects are linguistic or cultural artifacts (the objectified mind; Throop 2002).

Experience-near methods sacrifice breadth for depth. However, this kind of sampling and methodology, while drawing on data from fewer participants, pushes beyond initial characterizations and explores how concepts interact with experiential and cognitive and affective processes (Levy and Hollan 2015; Lende 2005). Together, experience-near methods seek to understand “emotional saliency and motivational force of cultural beliefs, symbols, and structures, rather than to assume such saliency and force” (Levy and Hollan 2015, 313). Experience-near interviews were primarily used to understand pwSCI participants’ (n=15) emotional worlds, reactions, thoughts, and feelings about therapy, their debilitated condition, and their relationships with others. However, such interview data are combined with observations and interactions with participants on the therapy floor in order to triangulate participants’ internal worlds adequately.

This approach enabled me to analyze together the subjective norms and the cultural values present at KP. As used in this dissertation, experience-near methods are akin to case studies, where a “researcher explores in depth a program, event, activity, process, or one or more individuals. The case(s) are bounded by time and activity, and researchers collect detailed

information using a variety of data collection procedures over a sustained period of time” (Cresswell 2014, 290). Additionally, experience-near interviews are in depth interviews focused on participants’ experience, emotions, and feelings. Of the fifteen pwSCI participants involved in this research, 14 experience-near interviews were conducted with 10 individuals (all listed above in Table 2). As indicated, four interlocutors provided experience-near information, but all within the same interview session as semi-structured interviews.

Semi-structured Interviews

Fifty-eight semi-structured interviews were conducted with forty-four individuals from four key groups—pwSCI (n=15), their caretakers (n=7), rehabilitation administrators/advocates (n=2), and rehabilitation staff (n=20). I sought to understand experiences, values, and attitudes by interviewing pwSCI. Similarly, interviewing family members helped interrogate family members’ own experiences negotiating the procedures of pwSCI care as well as the bureaucratic process they became adept at navigating. SCI advocates and KP staff provided additional insight into pwSCI—one through an affiliative advocacy role and the other from a biomedical perspective. All of these groups provided context into the sociocultural environments in which SCI exists—intersubjectively and phenomenologically.

Data Analysis

Interviews were initially coded using in-situ coding where participant words and phrases were used to create initial analytical categories. Initial coding was performed during the interviews where certain words and phrases were noted. Subsequent in situ coding occurred upon initial read through. Thematic coding subsequently occurred by collating these multiple diffuse codes into broader themes. This occurred repeatedly alongside each new interview conducted.

This process helped to place different interviews into conversation with one another in order to tease out the similarities and differences between both the data and the participants. This iterative process of lumping and splitting aided in creating a more reliable interpretation of these data.

Limitations

These methods as well as this dissertation's focus on pwSCI who are active in rehabilitation created some inherent limitation in these data. First, while all rehabilitation participants' sessions were attended, only a few agreed to chat in an interview. In addition, several participants initially agreed to participate, but subsequently fell out of contact or later withdrew interest. As such, it is impossible to explore whether there were any confounding factors that contributed to their non-participation as participation would be necessary to determine this.

Secondly, the nature of a robust qualitative study such as this is concerned with specificity in order to parse out specific cultural contexts and how many of the phenomena captured engage with the culturality defined at KP. As such, generalization of findings is neither possible nor desired. However, this dissertation serves as a case study for the theoretical model defined in chapter 2, which may indeed be generalizable across settings and participant types. Subsequent explorations can be taken by other anthropologists and social scientists in order to further explore this.

Lastly, and most crucially, these data focus specifically on those pursuing rehabilitation. Given the data on sociality, disability, and various psychological and physical health outcomes, it is likely that focusing on rehabilitation participants serves as an effect modifier of the interpretive themes to be described in later chapters; namely, with regard to hope, optimistic versus pessimistic outcomes, and larger discussions of sociality. If a person is pursuing

rehabilitation (especially an incredibly social one like ABT at KP), it is likely that they are generally more social than those who do not and who may live their lives in more reclusion. Importantly, those who do not attend rehabilitation are perhaps the most invisible as their lack of attendance rendered them invisible in the dissertation. This creates a very straightforward path for future research: focusing on those not represented here as their experiences are equally as deserving of being explored and centered in considerations about hope and well-being for persons with SCI.

Chapter Four: The Moral Economy of SCI Care

Didier Fassin has done the most to theorize the concept of a moral economy in anthropology (Fassin 2005, 2009, 2012, 2015). Originally derived from EP Thompson (1971, 79), the moral economy originally referred to the norms and obligations that arise from the existing economic functions of those within a given community. In Thompson's original formulation, it interrogated how individuals might behave as a result of e.g., food scarcity (such as looting resulting from unjust bread prices). Here, morality is tied to socioeconomic conditions. A "moral" economy works in tandem with the economy of resources in which a moral calculus is immanent to human social life. The moral springs forth from this situational bedrock.

Fassin builds on this to define the moral economy as (1) involving normative values and standards (Fassin 2005) as well as to examine (2) how morality itself gets circulated, produced, and distributed throughout social spaces (Fassin 2012, 266). In the former, moral economy functions to grant near-hegemonic access and social power (in terms of authority and what a person is enabled to do) to individuals differentially. This is similar to notions of deservingness theorized in migrant scholarship where certain people, on account of their migration status, are seen as less deserving (Castañeda et al. 2015; Willen et al. 2017), and perhaps even "unsanitary citizens" (Briggs and Mantini-Briggs 2003). Social advantages are granted to different people, with moral standards circulating within a society through different dis/authorizing processes. These processes are relevant for this dissertation, as pwSCI discussed in this chapter are differentially defined on account of veteran status, level of ability/impairment, and history of drug use – each serving to either qualify or disqualify patients from dignity and care.

Fassin's latter innovation of moral economy serves to describe morality analogically, wherein moral sentiments and standards move through and permeate a sociocultural landscape in much the same way as commodities flow through society. Especially noteworthy in Fassin's elaboration of moral economies is his attention to emotions and values that underlie these everyday processes, hence his definition of moral economies as "the production, distribution, circulation, and use of moral sentiments, emotions and values, and norms and obligations in social space" (Fassin 2009, 37). He argues further that "emotions are not separate from values or norms" (ibid.). This is crucial to my theorizing, as I have argued in Chapter 2 that morality and emotions often go hand in hand as they are both end results – the interpretation that gets communicated in social interactions. They are capable of being enunciated and enforced via social rules. As I present below, moral judgments can often be communicated and enforced through emotional appeals. Thus, much of what people at KP communicate thinking and feeling can be quite difficult to separate from one another as, I argue, they both result from a more immanent, ethical affective (primary level) basis that will be further elaborated in later chapters (Chapters 6 and 7).

How Therapeutic Encounters Lead to New SCI Constructs

Yeah, I was going to [Hospital] for a while. There were just so many limitations. Time. Insurance. And everyone is worried about liability. They constantly wanted me to submit evaluations. But then they didn't let me go to anymore sessions. All they said was that I was too good to have goals. Like, really? It's a great trauma hospital, but not great for rehab. It's like a factory: get them in and out. I heard people often don't get more than a year. I was so sad after leaving Shepherd's and then [having that experience] at [Hospital].

-Caitlyn

The excerpt above is from Caitlyn, a 45-year-old woman with a C6, quadriplegia-level injury, who has the use of her arms, but little finger dexterity. Her experience at a nearby major hospital touches on an issue that many at KP expressed: how they were defined, and how that affected their in/ability to receive physical therapy. As Caitlyn indicates, a statement that seems to express complimentary sentiments in practice has detrimental effects as she can no longer have insurance-funded, outpatient hospital rehabilitation.

Many at KP described experiences where they felt their own injuries being objectified, bringing about transformations in their own illness experiences. Indeed, Byron Good (1994, 68) argues that despite its claims to objectivity, medicine is still embedded within cultural paradigms that organize the world into “distinctive forms of reality.” While data below cannot speak to these paradigms outside of that instituted at KP, it is clear that despite how pwSCIs at KP internalized claims of medicine as being a “mirror of nature” (Good 1994, 5), these experiences are revealed to be partial, situated, and consequential knowledges (Haraway 1988) due to patients’ own narrative transformations and positionalities. In other words, patients’ and clients’ own ethical normative frames can be extracted by analyzing their experiences (both personal and bureaucratic).

In the following sections, I present four case studies in order to illustrate three different dimensions of difference between patients/clients: veteran status, level of impairment/disability, and history of drug use. All will be discussed together after the four case studies have been illustrated. The first case study involves Tom, whose veteran status differentially qualifies him for health services that not all pwSCI qualify for. For patients/clients such as Caitlyn (above), she describes how her physicians have deemed her injury as “too good,” which is a compliment

betrayed by the restrictions that result. Many, if not all, who attend rehabilitation at KP describe instances where their doctors told them that recovery was simply impossible. Many at KP understood this to mean they were beyond hope; however, the extent to which this is imposed on them varies. The following two case studies exemplify this theme while tying together other aspects experienced by patients/clients at KP.

The Case of Tom: Inherent Limitations and Double Binds

One participant at KP named Tom is a 30-year-old veteran injured for eleven years with both a T4 complete spinal cord injury (resulting in paralysis from the T4 thoracic vertebrae, around the chest area, down) and traumatic brain injury (TBI) due to a stroke incurred during an early lifesaving surgery that left him with reduced physical function on the left side of his body. This comorbidity results in a combined condition that Tom terms “triplegia” – a space between paraplegia (which affects the lower limbs) and quadriplegia/tetraplegia (which affects all four limbs). As an example of activity-based therapy (ABT) in action, Tom’s physical therapists at KP do a range of exercises to help him perform holistic functional movements, such as being on all fours, which requires that therapists and trainers support Tom’s body while ensuring that his body weight is properly on his knees and both of his hands, with Tom assisting with these movements as much as possible.

Tom has full control over his right arm but suffers from some significant contractures (joint rigidity due to the shortening or hardening of one’s muscles or tendons) in his left shoulder, elbow, and hand. The benefits of performing these types of exercises have been largely supported in the medical and rehabilitation literature, including increases in walking ability (Jones et al. 2014), functional independence (de Oliveira et al. 2019), and bowel, bladder, and sexual function (Hubscher et al. 2018), the latter being especially tied to increased quality of life

for pwSCI (Elliott 2013). Despite these seemingly clear benefits, it is also understood that the rate of recovery from SCI is largely contingent on the nature of injury. Recovery is never technically foreclosed, but it is also understood that some injuries are so severe that while a person may be able to strengthen whatever functions they have, hopes of walking again may never be achieved.

Unfortunately, bureaucratic processes seldom acknowledge this inherent ambiguity. According to Tom, his primary care physician (PCP) recommends, to Tom and his father (Tom's primary caretaker) that weight bearing therapies like ABT performed at KP confer no benefits, and if Tom were to break a leg while in a standing frame (a supportive sling that allows patients to perform supported walking exercises), then there would be absolutely nothing he could do to help him.

Doctors told Tom that he would never be able to feel nor fully extend his left arm – yet, over time he has developed sensations in his arm and can extend it quite significantly. Nonetheless, he explains that his doctors attribute this to his stretching and to the natural recovery of his body, and that he could accomplish just as much (and with less risks) without ABT. Indeed, risk plays a large role in the lives of pwSCI – as indicated by Caitlyn above – whether attempting to diminish it or engaging with it to increase one's recovery. Tom's doctors determine that therapies such as ABT create increased avoidable risks in their patient's lives. However, most importantly, physicians take different roles in the lives of their patients. For Tom, he explains that his PCP is concerned for his well-being, but he ultimately gives Tom the choice of whether to pursue ABT or not.

Tom experiences his subject position as a double bind. Most importantly, Bateson and colleagues (1962, 155) consider the double bind as incongruent communication that occurs on

different communicative channels resulting in varying levels of distress for those individuals experiencing it. Relevantly, Tom is a veteran, and so is well taken care of financially. Yes, he's had doctors tell him not to do ABT because it doesn't offer many (if any) benefits, but they also leave the decision up to him, giving him the prescription necessary to pursue rehabilitation covered under his insurance.⁴ The reason Tom's insurance is so robust is because he is designated as 100% disabled/dependent, even though he has quite a bit of independence. However, this designation is due to his TBI, which in combination with his SCI, affects every region of his body. In many ways, his ability to have a given vision is reinforced. And in others, he is discouraged and told to have no hope. He's deemed 100% disabled, which grants him health care and financial security, but it is also a designation that is the most discouraging for a person hoping to recover.

Tom is a strong advocate for the kind of ABT practiced at KP, telling me that in his 6 years of attending therapy, he's able to move his left arm more easily, and has gained significant core control, allowing him to balance in his chair, granting him a level of independence that he otherwise wouldn't have. Clearly, he has made improvements. Tom also tells me that while hopes of a "cure" are often prioritized for those with SCI, that, "I think the cure would be great, but for me I don't think I want a fix. I figure I'm still here for something and getting that would make me distracted from whatever I need to do while I'm still alive and kicking... I guess being on my chair reminds me I'm sitting here for something." Thus, the kind of recovery Tom attains at KP is hopeful and constant, but the kind of quick recovery that a cure promises to grant him

⁴ To pursue therapy at KP, a patient's PCP as well as the physical therapist at KP must each report to the insurance company that their expert opinion is that a patient will benefit from this kind of therapy. Communication between physicians and physical therapists are seldom direct and are often mediated by either insurance companies or patients themselves.

detracts from the kind of growth that the last ten years he has spent with his condition has incited within him.

Tom's statements articulate a hope for the future, in which he can leverage what happened to him to bring about other types of radical change. However, Tom's PCP's statements may be partially illuminated by what one supervisor with the VA (where Tom regularly sees his PCP and receives other care resources) I spoke with reasoned regarding the type of care they provide to patients: that it is a lifelong care that "evolves with the evolving needs of the veteran over time." The VA supervisor felt that ABT centers like KP practice, "Alternative therapies that may or may not be a best practice... Medicine has shown that doing these exercises daily doesn't have a huge benefit. Hasn't shown any huge potential to regenerate feeling, mobility, stuff like that. But I am interested in some of these divergent modes of care." What is most relevant there is that ABT is itself a divergent mode of care; it is a therapy that diverges from what has been rigorously studied and instituted in a large system like the VA.

I argue, following Good (1994), that what counts as "evidence" is deeply ideological, and changes whether we look from the perspective of a behemoth such as the VA system, which offers care and recovery resources to its 27,000 SCI veterans across its 25 main SCI centers (VA n.d.) – which would average to about 1,080 patients per center – versus smaller nonprofits such as KP, which has a maximum of 55 unique patients per month and also receives much of its funding not only from insured patients, but also from donations from wealthy funders which help subsidize costs for self-pay clients.

Despite claims of what is more or less effective, what is most relevant here is how Tom experiences a regime of truth with inherent double binds with his being in the VA system. He is subscribed to a program without hope of recovery, and yet is enabled through funding and

insurance a means of pursuing it anyways. However, these considerations also exist in a second double bind where Tom lives in a quotidian tri-plegic state, yet is regularly told what an inspiration he is, or that he “should tell everyone my story.” Thus, I would hypothesize that the VA exists in a system that must prioritize care for thousands of veterans while ABT can execute such an ideal form of care only possible through a nonprofit, donor-supported structure. However, Tom exists in this field where his condition is interpellated as what Wool (2015, 5) describes as simultaneously extraordinary and ordinary. This extra/ordinary position depicts a disabled individual as quotidianly ordinary, yet interpellated as extraordinarily injured. Hence those recommendations to Tom that telling his story would be meaningful and powerful. It is the extraordinary that gives it weight.

For Tom, his rationalizations (signaling back to chapter 2: his logical, secondary-level expressions) – of wanting to make a difference for pwSCI – operates within boundaries formed for him by his extra/ordinary social norms, one where he is best geared towards sharing his war story to help illuminate the lives of others with his condition. In effect, boundaries are drawn around him because of his condition through an ontopolitical process that has effectively prescribed his limits. In addition, these efforts work to create new possibilities for pwSCI, one where there is greater accessibility for wheelchairs in public spaces, and one where people with this condition can be more easily integrated into social environments. This is the context in which “not wanting a cure” exists.

This understanding helps illuminate Tom’s alternative perspective, where he states that he, “wouldn’t want to live very long this way,” a statement that seems to contradict his assertions of not wanting a “cure” at all. However, no contradiction exists between these statements if we understand Tom as communicating on two different subjective levels: the social moral (what

category of person he exists within and what should exist to help it) and the personal affective (the everydayness of living with SCI). The next case study, Jessica, illustrates the presence of other tensions that pwSCI experience.

The Case of Jessica: SCI as Transcendent

Jessica is a 40-year-old mother of two who has been injured for 3 years following a car accident. She describes how KP has helped her make advancements in her recovery. She “was told from [Hospital] that I would never have triceps, that I would never be in a manual chair, that I would never be able to move my legs, or do this or do that, but KP has done that.” Jessica explains that at a nearby hospital, she was told she would never be able to develop strong triceps, move her legs, but at KP, she has developed triceps. She’s developed them so much that she can now transfer herself to and from her chair unassisted. Thus, ABT at KP offers her the kind of hope that she claims physicians and traditional forms of therapy “take away” from her. After all, she only practiced rehabilitation at the local hospital for a few months before being told she could not attend them anymore.

Jessica cares for her two sons, a 17-year-old and a 6-year-old, alongside her boyfriend. Her injury was the result of a hit-and-run that occurred in the early hours of the morning when she was driving from her boyfriend’s house back to her own. Because she wore the shoulder strap portion of the seatbelt around her back rather than over her shoulder, the police officer that eventually arrived on the scene designated her as “not wearing a seatbelt,” and thus, in Jessica’s words, a “reckless” driver. Jessica deems her situation as one where, “I would not wish, I would not wish this on any of my enemies, you know? Even... even like the person that I just like... want to be gone. I would... I would not wish that on them because it's not something that you want to go through.”

For Jessica, the transcendental limit that SCI imposes on the body transcends the boundaries between “enemy” and “friend,” albeit hypothetically. The tragedy of being fully abled one day, and completely paralyzed the next is an idea that circulates around KP. Patients/clients, therapists, and caretakers find different ways of coping with them. For instance, Jack, a physical therapy assistant (PTA) at KP, says “My own issues that I complain about for the first five minutes of the day—as soon as I come here, none of that shit matters. Perspective. People have different problems.” SCI comprises a transcendental state for both patients and staff at KP.

All hardships, injuries, and pain are compared with paralysis. Able centrism offers a counter transcendence to the transcendental of SCI itself. Yet, both transcendentals reify one reality – where ability is best, and when this isn’t possible, just do the best that you can. SCI thus comprises a transcendent experience in terms of being a quintessential suffering position. How do these themes evoked by Tom’s and Jessica’s case studies (i.e., inherent limitations in recovery, an extra/ordinary and biomedical double bind, and SCI as transcendent) play out in the kind of therapy performed at KP? Indeed, KP uses its own set of moral enunciations and language to define itself, often contra, the kind of typical therapies provided elsewhere.

These considerations generate two questions here: first, what happens when hope is linked to one definition of “capability”? ABT at KP seems to reinforce the kind of active, “overcoming” narratives that disability scholars often critique (Bloom 2019; Rembis 2013). However, secondly, what happens to hope when we place limits on what constitutes good care practice? The first question speaks to able normative standards. These are often inherent and instituted through daily practices and utterances – in this case, on the side of the medical and health professionals surrounding SCI patients. The second question speaks to norms of a

different kind: how structures themselves define what ought to be practiced. Rather than based solely on bodily healing, pwSCI must often consider how a given set of activities may place them at greater or lesser risk. Returning to the VA administrator's claim, I argue that using a terminology of "evidence-based medicine" and established "modes of care" obscures the inherent moral quality of these statements, further contextualizing what pwSCI at KP experience. The next case study, David, provides a sharp deviation from how pwSCI at KP interpret the kinds of messaging provided to Jessica: a case where bodily recovery is enabled because of what is deemed as more tangible progress.

The Case of David: Motivation as Differentially Supported

For physicians, hope seems to lie in the potential for recovery. If it doesn't, then it must lie in finding a new life worth living that considers the fundamental transformation that has taken place. Consider David, a 21-year-old man who attends sessions at KP, and who has made several advancements in his recovery, despite his initial diagnosis being deemed a "complete injury" – meaning that his spinal cord has sustained complete damage. A complete injury also implies that recovery is unlikely. Yet, David has started walking again, albeit with some strain and hesitation. He explains, "I've had to build my legs back from nothing, which takes hours of work... my doctors said it was like an explosion in my spine, so I'd be able to make no progress. They called it a burst fracture. But I think my hard work and dedication is the game changer. They now say it's an incomplete injury." David explains that during the surgery to treat his "burst fracture," as his doctors referred to his injury, his surgeons "used tweezers to remove spinal fragments and some cord."

David sustained his injury at his L3 vertebrae while he was attending a military academy in Alabama a year and a half earlier. He fell about 45 feet from a rappel tower, breaking his back.

He was initially told he would never be able to walk again, and at the time I met him, he had been attending rehabilitation at KP for 8 months. He mentions that he is hoping to one day “say bye to this (pointing at his wheelchair) for good.” David first went to the local hospital, then when COVID hit, they shut down their remote rehabilitation facility, causing him to attend therapy at another of their nearby locations, which is where he got to use their exoskeleton – a supportive, battery-operated frame that helps patients walk unassisted.

Despite these various resources at its facilities, David believes that “[Hospital] didn’t do the proper care,” mainly because their sessions only last 45 minutes, which gives just 20-30 minutes to do a whole workout. He states that one “can’t get a proper workout,” especially somebody like him, who “was trying to rebuild my legs from nothing.” In order to make real progress, he would “have to put in hours of work.” At KP, David sees the care as more dynamic and fluid. The ability to request exercises here at KP is crucial for him. He explains, “No offense to this place. [Hospital] has better facilities. But here the care is much better.” “They said I’d be extremely lucky to get any progress,” on account of David’s injury, and the details of medical professionals having to remove damaged vertebra and spinal cord. Despite these limitations, David claims that “hard work and determination is the game changer.”

Given these data, one can only ask, how arbitrary are these standards and designations that are supposed to say something about the body? Indeed, they have weight in the kinds of actions they propel in patients, and the kinds of attitudes they develop about them. For some, such as Tom and Jessica, they are supposed to minimize risk, and for others, such as David, the progress is so undeniable that not even doctors recommend stopping. This is relevant for how pwSCI at KP interpret these messages. For instance, David attributes his recovery to his hard

work and dedication, yet how much of this is simply due to the nature of the injury? As the lead trainer at KP, Daniel, explains:

the neurological aspect of these injuries is so vastly different between one person to another, you can never assume that one person is going to be better because you would always want to-- if you just had a general notion of spinal cord injuries, you would assume that someone with a T3 level of injury can sit up pretty well without having to hold themselves up versus somebody that's like a C level injury. But what I've seen here with people I work with is just it doesn't matter what you know book-wise, it matters what is presented in front of you. Because I have a guy with the C4/5 level injury and he can sit better now than when he first started and he sits way better than some of our T3 level guys, you know what I mean. So, I mean it just depends on how the injury really affects your body.

“Hope” manifests itself differently in different bodies. I argue that what separates David from people like Tom and Jessica is merely the rate of recovery, which gets conflated with what is “possible.” Biological processes become laden with value in ways that have serious consequences. However, recovery for SCI patients never ceases to exist. Physicians merely determine whether it is worth the risk. “Hope” is thus a fraught concept that plays off the body and how it has been evaluated. However, this evaluation process can often leave some individuals more abandoned (or with seemingly less opportunities) than others. As indicated earlier, I believe these perceptions are crucial to disentangle as they provide insight into the various motivations and ethical stances of pwSCI rehabilitation participants. The final case study provides a contrast to all those which have passed. Here I interrogate notions of deservingness by posing the case of Matt, an individual whose medical and personal history offers moral ambiguity somewhat absent from all the previous cases.

The Case of Matt: Structural Justifications of Moral Deservingness

Matt's experiences more explicitly reveal the various gaps that can exist for pwSCI, as well as the immanently moral stance that biomedicine fashions for patients. Matt is a 50-year-old

man injured for 3 years. He explains that being a gay man with a history of substance use made his ability to seek care very difficult. “I was diagnosed with HIV and that is when the abscesses in my mouth started, and I kept getting infections... I was clean for 5 years when I started dating a guy who tried to kill me. I started using again soon after that.” The problems really started in Matt’s life when he was admitted in a hospital for substance use.

He describes how he complained of pains in his back but was ignored at the hospital he was admitted to, with some staff telling him that he wasn’t going to receive the drugs he clearly wanted. Despite the head of neurology recommending an MRI, he explains how the staff there “were so reticent to touch me, despite my undetectable status.” The hospital staff waited an additional three days before preparing Matt for surgery. By the time they treated him, the abscess that had formed in his neck grew and had caused damage to his spinal cord. “I beat myself up for returning to drugs and going into the IV side of it. But they didn’t have to treat me so badly.”

It was during my first interview with Matt, about eight months after first meeting him, that he told me that his primary caretaker, Karla, who he had previously introduced me to as his sister, was in fact a close friend who ended up taking on responsibility for his care. In fact, prior to this revelation, I had interviewed Karla about six months before my conversation with Matt, where she told me that she and Matt shared a mother, making them half siblings. This conversation took place at KP, which may explain her hesitancy to divulge this information to me then.

During my conversation with Matt, he explained that “to navigate the medical world, I had to describe her as my sister. Otherwise, she would never have been able to go back to my room or to have been advocating for me in any way, and there would have been no time for me to get anybody in my family to do that.” Thus, Matt jokes that Karla and he are “common law

siblings,” but that “if Karla hadn’t been there, I would have died.” It was thus necessary to claim siblinghood for Karla to legally be able to take on his care.

Relevant to his history of drug use, Matt and Karla first met through his being her sponsor in Alcoholics Anonymous, where they were introduced to one another at a Starbucks, with her presented to him as “a girl getting sober.” He describes Karla as an “extremely angry lady,” but over time she has come to “know more about me than any of my siblings.” Matt and Karla’s repeated experiences with hospitals is enabled by their being labeled “drug-using,” which justifies the “probably drug-seeking” designation that Matt and Karla each separately describe to me about their treatment since Matt’s injury.

It is fascinating that the bond created through AA between Matt and Karla has persisted so thoroughly that Matt describes how “my family is very loving and thankful [towards] her,” and trust her so much that even early on in his injury, “she was the point person.” Further, “She’s the only person I’ve let into my life... I’ve got people I’ve known a lot longer that don’t know me that well.” Indeed, despite his parents living nearby, all responsibility for his care is taken on by Karla, representing a drastic shift in their relationship – where caregiving roles are reversed with Matt formerly being Karla’s sponsor, to all of Matt’s care and well-being falling on Karla. What stands out most from these conversations is how they both exist in an awkward situation where they must struggle against how hospitals define Matt given his SCI.

Analyzing These Cases: KP as Moral Laboratory

It is tempting to see Matt’s case as unique or as an exception. I would hypothesize that his experience is merely the other side of the health system for pwSCI and its immanent moral judgment. In the cases above, we see that certain bodies are granted hope, like David. Some are given more support on account of the severity of their debilitation, such as Tom. Some have

shown a clear trajectory of improvement, such as Jessica and David. And some individuals like Kevin are financially able to spend more money out of pocket to grant themselves more control of their own care. However, in Matt's case, we see that he takes responsibility for his injury, explaining to me that "it was my own fault." And yet, he can't discount the disgust and judgment leveled upon him by hospital staff. "But they didn't have to treat me so badly." In order to tackle these directly, further research within hospital settings should explore how ethical imperatives are enacted in their clinics.

Nevertheless, the rehabilitation floor at KP does constitute a kind of "moral laboratory," to borrow from Cheryl Mattingly (2014), who describes everyday spaces (be they clinics or sports fields) as environments where individuals can enact and negotiate hopeful and alternative futures. The moral laboratory may also be the context where intersectionality plays out. The disparate contexts that these individuals in these case studies inhabit transcend their own categories, creating new experiences and interactions. Having a diverse set of insurances, injury levels, and definitions by physicians and rehab professionals leads to different illness experiences and outcomes. As such, David is granted more possibility and hope of recovery than many others at KP on account of his own injury particularities compared to many others at KP. Furthermore, at KP, pwSCI can negotiate their various experiences as well as their own injury in order to create new affects. I argue that while rehabilitation may reinforce able-normativity, it is also a means of expression – i.e., how we explore possibilities and alternative futures (Bruner 1986; Mattingly 2014). As such, the next two chapters will focus much more on normative affects and the various experiences that help to reshape and reorient that which pwSCI previously took for granted.

However, focusing on the emotional and moral dimensions of rehabilitation participants' experiences helps draw out their own subjecthood. Indeed, even this research process was an opportunity for participants to express their experiences, tell me their story, and teach someone about who they are, what they want, and where they want to go. PwSCI at KP taught me about the limits others place on them, and the various ways they go about challenging them. Even in Matt's case, attending rehabilitation is an empowering act. Each of my interlocutors also explained how KP is a family. Does striving for increased functional mobility reify normative ableism? Perhaps. But is suggesting that a person should adapt to their new life, and find social affordances through other means, not constitute another form of abandonment?

Mol (2007) cautions us from dichotomizing patient care from patient choice. In the spirit of patient choice, we risk instituting poor care. In prioritizing patient care, we risk ignoring patient agency, which may constitute another form of poor care – of respect and dignity. The form that “care” takes for pwSCI is often contingent on the judgments and assessments of doctors and other professionals. How might we go about balancing these different facets of patient embodiment and well-being?

I would like to problematize the advancements in physical functioning experienced by patients and clients at KP by interrogating the initial prognoses given, such as that indicated by the VA administrator above. To reiterate, the literature generally supports rehabilitation for all pwSCI, indicating that it can have modest effects on walking ability (Jones et al. 2014), functional independence (de Oliveira et al. 2019), and bowel, bladder, and sexual function (Hubscher et al. 2018). However, the rate of recovery varies widely, with individuals like David advancing quite rapidly and consistently, and others like Tom and Jessica having plateaued quite quickly. Yet, recovery has ceased for neither – Tom increasingly gains the use of his contracted

arm while Jessica keeps improving her ability to live independently, such as by improving her ability to transfer herself to and from her wheelchair.

Interestingly, many of the hopes existing for pwSCI at KP operate contra initial prognoses. PwSCI at KP describe a phenomenon where they are given strict boundaries that are easily defied. It seems that these instances of defying their initial odds serve to create a tension that wouldn't exist otherwise., propelling patients to pursue therapy on account of how those patients regularly defy the odds that doctors give them. As Carmen, the 32-year-old supervising physical therapist at KP (and under whose license KP provides all insurance and Medicare-funded care), explains, many patients have stories about overcoming certain limitations their doctors gave them, and now it's as if they believe that all is possible "because if they were wrong about that, then they could be wrong about everything." The issue is that the odds posed to patients may have been erroneous to begin with. I argue that patients engage more with the rational system (i.e., the object constructed by biomedicine) rather than with how neuroplasticity functions in relation to their own bodies and injuries.

This has significant implications for concepts like motivation and hope, which will be explored further in Chapter 7. However, I now switch to outlining the rational system that KP uses to provide care to its patients and clients. This helps to flesh out how patients and clients are supported by KP staff through this "divergent" mode of care.

The Moral Imperatives of SCI Rehabilitation at KP

While PCPs and other rehabilitation facilities give limits on rehabilitation's usefulness for certain pwSCI, KP and its staff articulate a new set of moral norms that they and clients/patients deem appropriate and necessary for instituting good care. These sets of practices

are illustrated by the following brief ethnographic vignette based on my participant observation fieldnotes.

As soon as I walk into KP, I meet Jerome, one of the four trainers who lead sessions with self-pay clients. Jerome asks me if there is anything he can help me with. I did not meet him yesterday on my first day at KP. I introduce myself and tell him that I am here interested in learning about how they practice activity-based therapy in comparison with regular therapy.

Walking through the therapy floor, which is setup in a large room where each patient-therapist or client-trainer team can see one another, I greet Devon, a training aide that I met the previous day. Devon picks up from yesterday's conversation, asking me how far I've gotten in the new show Squid Game. After this brief conversation, I go and check in with the Operations Manager, Katie. Katie tells me that the person Devon was stretching is someone I should "keep some distance from right now" since he is currently "in the angry phase" of post-injury recovery. He is on the same injury timeline as Beatriz, another client who attends rehabilitation at KP, except she comes in about 5 times per week while this young man comes in about twice. She tells me that Tom, a 30-year-old veteran, would be great to shadow with today.

When I ask her about today's clients, she walks over and grabs the clipboard outside of her door that has clients' names and who they are working with that day, which she later explains is left in this spot, but placed backwards in order to comply with HIPAA. She also later explains how she does not try to know people by their condition, which I think is an incredible way of approaching the patients/clients here.

I meet Tom, and as I walk towards the work bench/table that clients are placed from their chairs, I am greeted by Patrick, another training aide, who is supporting the supervising physical therapist Carmen (who is, aside from the operations manager Katie, the only one with a

Doctor of Physical Therapy [DPT] degree at KP), who is writing in a chart. I meet Patrick, who I introduce myself to, explaining exactly what I am doing there: shadowing the staff to learn more about how activity-based therapy practiced at KP. He tells me enthusiastically that I can shadow him today.

While Carmen is stretching Tom, Patrick comes over and asks, “What can I grab?” Tom responds: “I wanna tell you don’t ever come over here and ask me that.” Everyone breaks out in laughter. Next, Tom is lifted and seated off the edge of the bench, with Patrick talking to him about video games (“old” ones like Nintendo).

There are a few noteworthy points about this vignette that were later illuminated by additional ethnographic encounters, as well as various interviews with patients/clients and KP staff. The first is what Katie, KP’s Operations Manager, mentioned about how she and the staff at KP treat those who come seeking services. That they make it a point to “get people up and out of their chairs.” She tells me that with

typical traditional physical therapy, you're going to get 45 to 50 minutes of care. And you've seen our sessions. But [with them] the majority of time you're not even going to get out of your chair. And a lot of the time, you will have one person who also may be treating another person at the same time, so you're going to have divided attention at best. So with us, you get the two hours of care. You always not only get out of your chair, but we get you in some sort of weight bearing which is important for your bones. It's important for your circulation. It's important for your digestion. It's important for your blood pressure.

Both the PTA Jack and the lead trainer Daniel further explain that taking patients and clients out of their chairs is the correct practice not only because it effectively engages the body, but also because it is necessary to provide, per Jack, “what a person needs to transfer from chair to bed.” Thus, to provide the kind of neuroplastic transformations, and maximize therapy’s ability to do this, the large, flat bench is necessary to start patients/clients from a more neutral ground from which KP staff can work up.

Indeed, the chair itself takes on a fascinating duality at KP. As indicated above, whether a therapeutic service makes the effort to place a patient out of his or her chair is crucial to whether it will be at all effective. KP's founder describes how he searched "for a good rehabilitation center where I would be out of my chair and get as fit as possible." Indeed, this is reflected in what Daniel, KP's lead trainer, tells me: that "Others have said how outpatient therapy at [Hospital] gets repetitive and there are no making more strides. Instead, it meets its organizational goals and that is it." However, at KP, instead of being metric-centered, they describe being client/patient centered. All goals are tailored to the person and what they want for themselves. "Because every body is different, so is every care plan."

There is a distinction common among KP staff about how they understand their practice versus how they understand "normal" rehabilitation practice. As reflected in the case studies above, therapists and trainers at KP define their services as less restrictive. As Daniel suggests, "We will never take that hope away from someone. That's not our place." However, he also explains that,

Obviously, a lot of people are going to want to walk again... yeah that's gonna... that's probably why most of the goals [elsewhere] are set by someone else. But I mean you can also say, "hey so I know you want to walk again, but there's gotta be some other stuff that you want to do." Like, approach it that way you know what I mean? So, they'll say, "My arms have been a little bit weak, and I feel like I could sit up a little better cause my posture... because I've been in my chair all day," you know what I mean? Like, if you just let them settle on, "I want to walk again," cool you know, but if you can build a better relationship with them, let them talk to you about like, "You know I'm starting to notice I'm leaning like a little bit like this," or, "My left arm is getting weaker than my right, what can I do to fix that?" And then we can reach more realistic goals for the client versus what has already been set for them.

A big distinction here lies in what is useful versus what patients'/clients' goals are. They are not always the same. Daniel explains that instituting good care means giving participants what they want in the long-term by prioritizing what will be functionally helpful in the short term. This is

echoed by what another PTA at KP, Jared – a 21-year-old who started working at KP a month after I began fieldwork there – tells me can be difficult: that building up walking ability means building up other bodily strengths and functions. Jared explains that, for instance, a person may have trouble walking because they do not have much core strength. And so, hope for walking can motivate them to practice walking, thereby detracting from the next feasible (and realistically helpful) step that patients would derive more benefits from, such as core exercises.

KP staff clearly have some ways of qualifying what is considered good therapeutic practice. However, much of this is learned at KP, which in KP parlance is more “neuro” focused as opposed to most physical therapy centers, which are considered more localized to one part of the body. This is explained by Jared, who explains that, “In school they taught more about procedural rehab,” where he learned about “tears, sprains, knee replacements.” However,

[At KP], we’re not targeting one thing. It’s kind of all over the place. So, it’s honestly very different. It’s a lot more aggressive as well. It’s not just one thing, it’s a whole task. So, we have to teach them how to combine all of what they have at the moment, strength-wise, to complete a task. So, it’s not just, “bring your arm up to your hand” you know. For like scooting, hand placement, [how] your body is gonna be spaced. How they have to shift and use their momentum. Thrusting their hips over. And doing it as safe as they can, so that they know their limits. And how far they can bring themselves forward, you know, “where I can bring myself up.” So, it’s a lot of different things at once. It’s not just, “flex your arm,” “bring your leg up.” It’s like ten steps compared to just one. And traditional therapy is just one.

For KP staff, they understand their therapy modality to be long-term as opposed to short-term; total body as opposed to localized; creative as opposed to procedural; relational as opposed to bureaucratic; and cultivating hopefulness as opposed to hopelessness.

How KP staff situates its ABT practice is, I argue, inherently moral, which I draw out further in chapter 5 and at the start of chapter 6. As Daniel explains, other rehabilitation facilities don’t practice ABT because,

they do think it's risky, but then, on the other end it's like... they've got a lot of government money, what if the opportunity comes around your patient can stand without assistance, whether it's some sort of epidural stimulator, some breakthrough in stem cell treatment. Whatever it is, you know they-- tomorrow, some breakthrough came, and they had the ability to stand up and move around with a without assistance. What's more risky? Having someone standing before this, or having someone stand after that, having never stood before?

For KP staff, integrating rigorous therapies in patients' lives at least holds future possibilities as possibilities, rather than foreclosing them altogether. Alternatively, institutions like the VA system and the major local hospital, despite having copious government funding, close off such possibilities when they limit a patient's ability to pursue rehabilitation at their facilities. Indeed, the reason why patients such as Caitlyn, Tom, Jessica, and David can contrast their experiences between the VA and the local hospital with KP is because they were provided limitations, often in their ability to attend rehabilitation at all.

On the one hand, this illuminates that patients/clients at KP are a very specific population of individuals who were, by definition, alienated by these systems. This may indicate bias. While data presented above cannot speak to these claims directly, what is clear is that the sociality and morality instituted at KP exists in oppositional tension to how "physicians," "traditional therapy," and "hospitals" are narratively constructed there. However, I argue that this makes KP's participants a specific population of individuals who have experiences, in some way, limitations in their rehabilitation, and thus pursued rehabilitation that caters to their specific wants and needs. ABT at KP fills this need. Additionally, the morality of providing active therapies at KP are communicated by both patients/clients and KP staff.

Discussion

This chapter reviewed how social location and situatedness structured the kinds of experiences patients and clients had in their disability experiences in and outside of KP on

account of their veteran status, level of impairment, and history of drug use. Individuals' bodies are deemed as more or less capable on account of their rate of recovery, which was defined differently at other rehabilitation care centers, which may harbor a different moral imperative than KP. Thus, statements about recovery expectations and hope, such as the idea that ABT at KP is not beneficial or is even risky and harmful, can be placed in an alternative institutional context as rehabilitation is generally shown to aid patients/clients in a multitude of ways, from quality of life to functional mobility outcomes. "Evidence" might also be situated within this rational, moral structure. However, data presented help outline how pwSCI at KP construct their own presence there through these narrative tensions.

This chapter also introduced the double bind affecting pwSCI, which will re-emerge throughout this dissertation. This double bind is enacted differently per pwSCI, but generally illuminates how patients/clients inhabit a new, normative space in their lives of debilitation, but are defined by others as inhabiting an extraordinary space in US culture. This is elaborated in Chapter 6 as I explain how SCI is seen as a transcendental condition that jars KP staff and its rehab participants out of daily cognitive loops of "complaining" and self-pity.

Lastly, this chapter also illustrated how one's rate of recovery can structure the kinds of messages received, and hope instilled in one's injury prognosis. Despite being defined as beyond recovery given the extent and gruesome state of his original injury, David felt that he defied all physician prognosis, leading him to situate the difference in his own motivational drive, rather than in physician diagnosis of his injury as complete and stagnant. Indeed, in the next chapters, I tackle this issue further, arguing that such diagnoses create an image that pwSCI struggle to counter, leading to some unintended consequences and challenges for KP staff.

The core issue that brings together all these disparate case studies is that the SCI care apparatus is immanently moral, and that this moral judgment is highly contingent on how it deems patients as differentially deserving. The KP therapy floor thus serves as a moral laboratory where rehab participants can enact different identities and capabilities that they otherwise cannot experience in their lives – where rehab professionals take them out of their chairs and see what they’re capable of doing.

At the end of this chapter, I explicitly showed how KP staff and rehab participants situate their activities contra “traditional” rehab. The structuralist-like categories presented above (which include long-term : short-term :: total-body : localized :: creative : procedural :: relational : bureaucratic :: hopeful : hopeless), as indicated by Daniel, Jack, Carmen, and Jared, all place KP and its practice in a different stance. These considerations are how KP defines itself in relation to alternative therapies. However, I argue that these moral categories are best illuminated by exploring KP’s regimes of truth, such as its primary category of identification: active versus passive. In the next chapters, I interrogate this active: passive dichotomy as this form of self-identification reinforces some attitudes and may provide a means for some of its clients/patients to fall through the cracks – especially when they do not fully conform to these standards.

Chapter Five: The Structures Driving SCI Rehabilitation Logics at KP

Over the course of my time at KP, it became clear that the distinction between patients and clients was far from inconsequential. Patients were those individuals whose debilitated bodily states were deemed by their insurance or Medicare as eligible for rehabilitation therapy. Clients are those who, as a result of being deemed ineligible, instead pay for their sessions out of pocket. As discussed in the previous chapter, biologically, “evidence” shows that all bodies can benefit from active therapy techniques; hence the recommendation that newly injured pwSCI pursue therapy within the first-year post-injury period, when medical professionals argue they can reap the most benefits (DeJong et al. 2013; Nas et al. 2015; Petersen et al. 2012).

A landmark case for long-term disability facilities like KP is the *Jimmo v. Sebelius* decision in 2013, which stated that Medicare would determine insurance eligibility based on a patient’s need for skilled care (which would prevent deterioration of existing health conditions) and not on one’s potential for improvement (CMS 2020). In other words, Medicare would fund maintenance therapies, and not only therapies that would bring about expedient bodily recovery. Despite this, many patients with SCI at KP do not necessarily qualify for Medicare, since those under age 65 do not qualify until two years after injury – a year longer than the first-year period for SCI patients.

Jessica, discussed in the last chapter, explains how she did not qualify for rehabilitation until after this period. However, she was able to pursue other options because her “SCI coordinator,” a resource option provided to newly injured individuals via Tampa General Hospital, helped link her to various care resources – which is how she came to find out about KP.

To add context to this, this chapter presents a few patients' cases, fleshing out the kinds of systems participants at KP are involved in, and how they each uniquely attend to them given their financial and temporal availability. Cases henceforth presented deal with the VA system, private insurance, and Medicare, which each structure patient experience distinctly.

Regimes of Truth: How Insurance Logics Organize Therapy at KP

Jamie: A Veteran Enabled Hope

Jamie is a 26-year-old African American woman who had been attending rehabilitation at KP for 6 months when I first met her. She was injured five years prior as she was leaving from having just re-enlisted in the military near her hometown of Montgomery, Alabama. She was asleep in the backseat of the recruiter's military vehicle – she explains that she and her friend played rock-paper-scissors for who would get to sleep in the backseat during the long drive back. Jamie won the initial round, and all subsequent rounds after her friend requested they go for “2 out of 3.” During the drive as Jamie was asleep, a woman heading the opposite direction on the road had a heart attack behind the wheel of her car, slamming into the vehicle on the side where Jamie's head was resting, breaking her neck at C7 level.

Jamie was airlifted 35 minutes away to the University of Alabama Birmingham Hospital, where she would spend the next month and a half in the intensive care unit and placed on a ventilator. She was placed in a medical coma during her first 2 weeks there. While she was deemed a “complete” C7 injury, Jamie explains how she has made incredible progress in her recovery as indicated by her visit the day prior to our interview, to the VA, where Katie, a nurse there, expressed amazement at how well she was doing. Jamie states that her most recent achievement is “being able to stand unassisted for 21 seconds,” with the therapist only placing their hands on her knees to provide the needed resistance to do so.

Despite her “complete” injury status, Jamie explains that she is “not supposed to feel my abdominal area, my bowels. But I can tell when I’m cold, or when I have sore legs.” She attributes much of her recovery to her unwavering faith in God, stating that “faith without works is dead.” Jamie currently drives a 2019 Dodge Challenger, which she operates using hand controls. As we chat over Zoom, she also shows me the inside of her home, which she explains was a new build. The man contracted to build her home – which is a part of a planned community – worked with her to make it completely to her needs and specifications. She was able to purchase this house through a grant offered through the Semper Fi fund, which she found out about through the VA. This fund helped her build up her credit, and she qualified for additional financial grants through the VA and other organizations because her injury was deemed to be “100% service connected.”

The details of Jamie’s injury are fascinating as it took place when she was re-enlisting in the military and not actively serving. However, because the accident happened to her physically while she was in a U.S. military-owned vehicle, she qualifies for various resources as if she had been injured while on deployment. As such, Jamie was able to build up her credit, and qualified for a \$100,000 grant that (since the contractor of her home made her home adaptable without incurring extra costs) she was able to put directly towards her mortgage.

Jamie acknowledges that accepting the changes that happened to her body has been incredibly difficult, and she initially fell into a depression when she was living back home near her family in Alabama. “Accepting all of these changes has been hard.” Jamie heard about KP about four years before starting there, when she first met KP’s founder. However, it would be several years (from her injury in 2016 to 2021) before she would move to the Central Florida area in 2021, when she would be able to feasibly attend rehabilitation at KP. Jamie explains that

she is attentive to constantly progressing and growing, however that looks for her in rehabilitation and in life.

Jamie spends her days working out in her home gym, which allows her to stand herself up on her own, going to KP, and socializing with friends and a girlfriend that she has recently been seeing. Jamie explains that since her injury, she has “learned to listen to my body and pay attention to how I treat my body.” Dealing with nerve pain is the most difficult part of her injury, but the biggest learning curve has been attending to her mental health. She uses music as her outlet and gives me her name on Spotify: K.Jamie, where she uploads new songs at least once a month. Jamie also published a short book, purchasable on Amazon, where she discusses her story and how she has learned to cope with her injury.

There are many facets of Jamie’s story that resonate with last chapter’s case studies, such as the nature of her injury (complete) and how amazed medical professionals have been at the amount of progress she has made. Jamie regularly works with Diana, a 28-year-old PTA at KP, who expresses how Jamie’s story is one of the “coolest success stories,” as Jamie, “had no core stability when she first started here, but I can feel her muscle contractions,” indicating some increases in her functional mobility.

I would like to zero in on the number of resources she has been able to draw on, on account of her being fully covered by the VA. Like Tom, Jamie is considered significantly disabled on account of her having a C-level injury, designating her as quadriplegic. Jamie attends rehabilitation at KP for two days per week, which is fully covered by Tricare. In contrast, prior to qualifying for Medicare, Jessica explained how “I was only getting two days” covered by her insurance. Once again, there exist structural barriers aside from the potential of recovery of one’s

physical functioning. Some insurances pay, others don't, creating different financial burdens on individuals and their families.

The Governmentality of Insurance Structure at KP

Foucault (2008) defines governmentality as the establishment of a set of rules which enable us to define statements, actions, and behaviors as true or false (or, correct or incorrect). There is no real objectivity, only regimes of truth – where the regime is the legislative body of knowledge instituted in order to evaluate and designate human actions. These regimes of truth are also naturalized, and unquestioned, as they are guided by assumptions that enable certain practices to continue with hegemonic authority. For Foucault (2008, 19), the art of governing is fixed by how nature has been constructed – that is, how actions become evaluated is the *naturalized* process that often goes unquestioned.

Our unquestioning of these things are far from overt and violent, much like David Graeber's (2013a) definition of *consensus*, which he defines as, "coming up with a creative solution that nobody violently objects to" where "consensus does not mean unanimity." In Graeber's formulation, governmental practice is modest, covert, and hegemonic.

Governmentality is relevant here, given how the structure and logic of insurance organizes a great deal of therapeutic practice. At KP as well as all other non-profit rehabilitation centers in Florida, Medicare must negotiate payment for services for such centers to operate as legitimate medical rehabilitation centers. At KP, Medicare sets the standard for: what services will exist/be available (and ultimately paid for) and how much a center will calculate/justify the bill/charge for its services.⁵

⁵ While Medicare generally sets the standards, Michelle, the accountant at KP, explains how different insurances work at KP. As an example, for those covered by the VA's Tricare, approval must be given for every 15 visits; for Medicare, approval for continued care is given every 8-10 visits. She also explains that while Medicaid will never

Regimes of Care: How Medicare Structures What Exists at KP

Auditing has been defined as a cultural practice of accountability situated within, and enabled by, diverse political regimes (Strathern 2000, 1). Thus, there is no single kind of political or economic landscape in which the practice of auditing – i.e., evaluation practices stemming from finance and accounting that involves measures of quality and other assessments that have expanded into all other kinds of outcome measures – is more or less likely (ibid., 2). Such theorizing centers “audit as an actant” to grant agency to bureaucratic and institutional norms, practices, and ethics (ibid., 5). Much like Latourian actor network theory (ANT), literature on audit cultures elaborate that the institutional apparatus provides a normative structure that not only guides behavior, but also provides expectations and a rational ethics, naturalizing certain decisions over others. Yet, this can be expressed variously.

For example: the research by Jessica Mulligan (2017, 134) on how Obamacare (aka, the affordable care act; ACA) funding was institutionally bifurcated between state and federal will, and that many would-be beneficiaries in states like Florida – whose governor and legislatures acted to divest and defund, thereby withdrawing state support – tended to blame President Obama and the Democratic, liberal federal government for its failure in their states. Despite the ACA potentially benefitting all low-income Americans, the narrative of federal governmental exclusion pervaded Mulligan’s interlocutor’s stories – where such arguments played off political narratives about ACA’s “overstep” (ibid., 133-134). However, such fraught political narratives

cover as one’s primary insurance, it will always cover as secondary insurance to Medicare: “As a general rule, if Medicare pays, Medicaid always pays.” Clearly, insurance mandates designate how and when one may miss out on therapy to seek approval and mandatory oversight by physicians and therapists. Furthermore, some insurances do not cover therapies at all.

inhabit the secondary, rational level introduced in this dissertation, with would-be beneficiaries buying into dog whistle narratives promoted by Republic-run legislatures.

This stands somewhat apart from what I refer to as the tertiary level “regime of truth” – the institutional and “common sense” logic often used by social programs. The “regime of truth” for ACA is its auditing practice – which involved convoluted eligibility parameters and problematic means testing that distinguished “deserving” from “non-deserving” recipients (*ibid.*, 138). This mechanism of inclusion-exclusion is important for how it engages with stigma (e.g., being defined as “poor”); yet, as Mulligan argues, means testing, while problematic for its stigmatizing effects, remains a preferred method of programmatic evaluation. This auditing ethic is important for how it structures care at KP – the distinction between client and patient is institutionally clear. However, as pwSCI, all at KP qualify for assistance – at least eventually.

The case of 23-year-old Caleb, whose primary caretaker is his mother, Leslie, exemplifies this. Leslie explains how her family is counting the months until Caleb qualifies for Medicare, which she breaks down as “29 months after injury. Because you need 5 months to determine a diagnosis and then 2 years from that date to qualify. So, we are stuck with the bill until April, next year.” Such differences in insurance qualification have led to KP’s dual billing system – which I argue is a continuation of the regime of truth (tertiary level) introduced by US insurance qualification logics, which only partly involves the ACA.

First, medical billing at KP operates through calculating units, which are further specified using specific codes that designate the type of facility, service/care provided, and amount to be paid. Michelle, the accountant and sole billing person at KP, tells me that billing Medicare for physical therapy at KP only utilizes “6 or 7 codes, so it is not complicated,” referring to Current Procedural Terminology (CPT) codes that hospitals, surgery centers, or offices like KP use to bill

insurance. To be clear, there exist tens if not hundreds of CPT codes for physical therapy, but given the kinds of resources, machines, and the kind of facility KP is designated, only 6 CPT codes get utilized. KP offers no water therapy, utilize machines with only localized electrode options, and otherwise use modified versions of exercise equipment such as bosu balls, a bench press, and dumbbells. More specialized equipment would translate to increased ability to bill for alternate therapies; however, with a Medicare cap at 6 units, this still would not translate to increased billing power for KP. Michelle explains, “We need to enter the appropriate CPT codes,” in which units are timed. “They only allow 4 units for non-Medicare insurance and 6 units for Medicare.”

For instance, “Commercial carriers like Blue Cross/Blue Shield, UnitedHealthcare, (and Aetna) that are not Medicare plans will only cover 4 units.” For such patients, “we have to let them or their caregivers know that 2 units aren’t covered, so we need to negotiate something prior to them coming in.” This is also evidenced by Caleb’s situation, whose mother Leslie describes their insurance, Aetna, as “useless.” “It only covers about 60 visits per year, and it’s one of the better ones. And then it’s all out of pocket after that. But my son is in need of constant therapy.” As mentioned earlier, Leslie explains how “we are stuck with the bill until April, next year,” She explains how her family is in a “privileged position” to be able to “drop money like that,” at which point Caleb will qualify for Medicare. Leslie also explains how she can “only imagine” what it is like for families that are financially worse off. Clearly, the 2-year wait period for Medicare affects the lives of pwSCI – who physicians and researchers argue should be receiving therapy especially during the first two years after injury in order to ensure maximum gains in physical functioning.

Michelle explains that Caleb's family has opted for an insurance option where they pay out of pocket until they have paid the complete amount of their deductible, which is \$5,000.00. She explains that "a lot of our patients go to urologists and neurologists, so I'm not normally the only person that's billing them. So, they tend to meet their deductibles rapidly because they are being seen by so many different facilities." This is one strategy patients opt for as living with SCI tends to incur inevitable costs, especially prior to Medicare qualification. The VA's Tricare insurance often follows Medicare guidelines, making many of its processes identical for its patients. As a result, how Medicare negotiates with KP tends to dictate how other patients must pay for services.

Regimes of Care: How Billing at KP Structures Care

The primacy of Medicare is particularly relevant to the following two points: (1) how time works in relation to insurance billing, and (2) how not all staff members can be billed equally. To this latter point, as previously mentioned, Carmen's (the only physical therapy practitioner at KP with a Doctor of Physical Therapy) sessions are billed the most per unit while all PTAs are billed significantly less, about \$28 versus \$23 respectively. This can amount to \$168 versus \$138 respectively per therapy session with patients. In practice this translates to: "Carmen sees 4 patients per day, which is why she makes more money (laughing)." "We lose income with Jared seeing them versus Carmen because she is available." This tends to prioritize having higher skilled therapists on staff: because a facility can bill more per unit.

This focus around Medicare billing, I argue, also tends to structure how care is administered at KP. Carmen explains her practice at KP:

So, for insurance we have to worry about units. Like eight to 15 minutes. or eight to 22 minutes is like one unit. Self-pay doesn't have that, like, they don't bill units. They just pay like a set amount there here for, you know, the set amount of time. Here I'm like,

okay. Because you have to bill based on, like, certain codes and so, so I'll be like, "Okay, 15 minutes on the bike," so like 15 minutes is like at least one unit of this. And then, if I did this, and took another unit, and these two can kind of can be grouped together, so it's like 35 minutes combined time. Yeah, the self-pay doesn't have to worry about that. I mean it's nice to say, "Oh yeah we did 15 minutes on the bike," or, "we did 15 minutes of walking," that way, you have like- It also helps, like the other trainers, and the other therapists like, "Oh, they spent 15 minutes on here, so I'm expecting the same- to do about the same amount of time." Like, "I know they can handle this amount of time."

This lengthy excerpt is fascinating for a few reasons. First, Carmen explains the 8-to-22-minute logic of care at KP. Per her training, she explains the "8-minute rule," a well-known rule with various articles on the internet (written by licensed physical therapists) providing guidance to those seeking advice about Medicare billing (e.g., Fraticelli 2019; Jannenga 2019). While this heuristic is linked to Medicare billing guidelines, Carmen explains that this logic of 8-22 minutes becomes a way of measuring patient progress, with trainers also using this logic.

This rationalization reminds me of Deleuze's explanation of institutions as "procedures of satisfaction," where "the tendencies satisfied by such procedures neither trigger nor determine the procedures" (Deleuze 2004, 20). Such decisions are not always made via conscious awareness, nor straightforward cause-effect relations. As such, audit culture figures prominently here again, as the practice of auditing creates its own dogmatic truths due to how it intersects with popular narratives and the inevitable bridges and barriers individuals confront in seeking care (Brunson and Mulligan 2017). While "human utility presupposes tendencies," institutions signal unconscious models that are expressed through rituals (ibid.). In other words, rituals can illuminate the tertiary level logics (i.e., regimes of truth) that undergird institutional mechanisms.

At KP, the ritual of 8-to-22-minute sessions is no longer explained by Medicare rationales alone, and the tendency that becomes satisfied is that of measuring and comparing client progress. Again, the inclination to homogenize, to create continuity between bodies and afflictions that may share more stark differences than we think, expresses the difference-

predicated-on-identity image of thought discussed in chapter 2. This dogma becomes satisfied. Yet, this satisfaction does not explain this rule, which for self-pay clients operates with less oversight and requirement.

This is fascinating for the fact that many sessions at KP were identical. Given that all patients and clients at KP must be assessed by Carmen at their intake – where Carmen creates a plan of care for all, based on her physical therapy training – all inevitably conform to this logic. I'd like to use Steven's rehabilitation session as an example of this. Steven does not technically have a SCI but was diagnosed two years prior with transverse myelitis (TM), a rare condition with an unknown etiology, but occurs when one's immune system attacks one's spinal cord without any diagnosable or discernible cause. Steven's TM is in his thoracic vertebrae, around T6.

Steven's session conforms to the logic of the 8-to-22-minute rule, even though he is a self-pay client (rather than an insurance-covered patient). Here is his session breakdown from my fieldnotes:

- 10:02 AM Steven's legs are getting stretched by the training aide, Calvin.*
- 10:15 AM Armando, Steven's trainer, lays out the exercises he will be performing.*
- 10:25 AM Steven is placed on the gait assist machine that wraps around his waist, providing some pads where he can place his forearms. It is electricity-powered, allowing his trainer to raise him up and down, to provide some support for Steven. Steven is placed on his knees, and on a vibration platform, that Armando explains will help stimulate Steven's muscles to engage with the exercise. In this position, Steven performs hip thrusts.*

- 10:44 AM *Steven is fitted with a blue elastic cord attached to a second supportive machine placed behind him. He is instructed to stand up tall, with Armando regularly asking Steven, “Does it feel alright?”*
- 11:04 AM *Steven is relocated to the foot of the bench (opposite to where he was previously). Armando and Calvin place Steven on his back and alternate moving his legs forward and backward, explaining that they are “working on his hip flexion.” They use their hands as resistance on the frontward part of the exercise, instructing Steven to engage his muscles and push against them throughout.*
- 11:14 AM *Armando and Calvin begin walking Steven around the room with the same gait assist machine that they were previously using to just keep him elevated. The move around the room in a counterclockwise direction, passing around all of the other clients and patients exercising. Before beginning, Armando asks if Steven, Calvin, and I were ready. They do a total of four laps, and switch positions (with Armando cueing Steven’s walking movements manually with his hands, and Calvin guiding and pulling the gait assist machine along the path around the room) after each one. Armando cues Steven’s legs first, pushing and pulling on Steven’s legs.*
- 11:30 AM *Armando instructs everyone to go “back to the mat.” At the mat, Steven does some body twists with Calvin holding the other end to help provide some resistance with the elastic band, with Steven twisting his trunk to the left side.*
- 11:40 AM *The music that was playing (which today was mostly Hip-Hop songs, which included 50 Cent’s “21 Questions”) stops abruptly, with Armando joking that*

“Someone didn’t pay the bill,” and Daniel responding that, “We can’t work out without music. The WiFi seems to be down.”

11:45 AM The music comes back on. Steven is on his last set of twists. As he ends, he expresses that “My shoulder blades feel sore” from the extensions.

11:50 AM Steven is done with his exercises, with Armando and Calvin helping to put him back in his chair. Calvin begins to wipe down the bench and wrap up operations. It is lunch time.

As Steven is a client, his sessions do not need to add up to the required 83 minute minimum that would allow a facility to bill for 6 units. However, it is relevant that Armando accomplished this anyways, as his sessions would be billable as 6 units, if Steven were being paid by insurance and if Armando were at least a PTA. Given that sessions at KP are 2-hours long, it is quite easy for all sessions to mirror one another. Given the 8-minute rule of physical therapy, we see that even clients conform to therapy logics. Table 1 illustrates a more straightforward breakdown of this session.

Table 3. Breakdown of Steven’s Session.

Time	Activity
10:02 – 10:25 AM	Stretched (not billable)
10:25 - 10:43 AM (18m)	Exercise 1: gait assist machine; does hip thrusts from a knee position (CPT code: 97112 : Neuromuscular Re-Education)
10:44 – 11:03 AM (18m)	Exercise 2: still on gait assist, with extra elastic band placed around his waist; this time instructed to “stand up tall” (CPT code: 97110 : Therapeutic Exercise)
11:04 – 11:13 AM (9m)	Exercise 3: from his back; instructed to apply as much force as possible against his trainers’ weight (CPT code: 97140 : Manual Therapy)
11:14 – 11:29 AM (15m)	Exercise 4: Walks around the room with the assistance of the gait assist machine (CPT code: 97116 : Gait Training)

11:30 – 11:49 AM (19m) Exercise 5: With elastic bands providing some resistance, instructed to do some “body twists” (CPT code: **97110**: Therapeutic Exercise x2)
11:50 AM Session complete

Michelle explains that “We provide well over what we bill.” Indeed, given what Medicare limitations are, KP might benefit financially by reducing its normative and advertised 2-hour sessions. After all, Michelle explains, “When I worked at a doctor’s office, I saw this all of the time. Someone would put the patient on a machine, walk away, and then come back 12 minutes later, billing that as a unit. But that’s not right, because a requirement is that the PT be there the whole time, otherwise you can’t bill for that.” Unit restrictions (how Medicare limits to 6 units) means that, at least economically, by Michelle’s account, KP loses out on money by prioritizing 2-hour sessions instead of figuring out strategies that are more time- and resource-efficient.

This is echoed by Katie, KP’s operations manager, who explains, “We would never operate our business model, 2-hour sessions 2 people [per patient], would never be a viable for-profit.” For this reason, KP relies heavily on donations raised from a yearly fundraising event which raises hundreds of thousands of dollars which various donors give to KP – which pegs itself as catering to veterans, due to its founder’s stature in the local community. To be especially efficient, mathematically, Michelle explains that KP could provide 50-minute sessions like other rehabilitation facilities do. In fact, the insurance funding structure seems to support this. But KP’s donor-structure helps provide the full 2 hours that is morally required of KP – which identifies itself as an alternative model of ideal therapy for SCI patients. KP seems to find, through its donor structure and enabled by its non-profit status, a rationality that allows it to prioritize its services while still operating within a field determined by Medicare fee schedules.

However, this dominant structure still affects some of KP's clients, as indicated by Kevin's situation.

Insurance as Frustrating Rehabilitation Goals. Determinations about whether rehabilitation will be useful are left up to physicians and physical therapists, who must both write recommendations to patients' insurances. Patients like Kevin, a 65-year-old man injured for 11 years after a workplace injury, qualify for insurance to cover his rehabilitation sessions, but after being fed up with the bureaucratic process, he has opted to self-pay:

Insurance companies want a renewal record... When they evaluate whether you're making progress or not, they don't let you go to therapy anymore, so you lose your spot in line for a month and a half, and then you give them three weeks and they go, "Okay, you can go back to therapy." But by then you gotta wait three more weeks to get your spot back in therapy again so after six weeks and not doing nothing, then you start right back where you were last time.

Kevin has opted for more control over his care, which requires him to pay more out of pocket. But he has determined that this tradeoff is well worth the assurance that he will have the exact care he desires.

Kevin argues that Medicare would cover 36 hours per year, which would amount to less than one session per week. However, the structure at KP is such that going through Medicare would deprive him of access to its unlicensed trainers, who he prefers over the licensed physical therapists there.⁶ Kevin identifies insurance as a bureaucratic process that, at initial injury, made him "miss out on the first 3 months of therapy after my injury." Pertinently, Kevin has Medicare as processed through the Worker's Compensation program, which he describes as difficult to decipher, using the example that, "If I want my tube changed and I use my Medicare, they'll

⁶ This point about personal relations at KP and certain individuals' preferences will be fully fleshed out in the next chapter, Chapter 6. But relevant here, Kevin's preference may be due to his having attended rehabilitation at KP since it opened, and the trainers have been at KP the longest, with the longest serving PTA being there for just over a year, and the DPT being there only a few months.

want to throw me in jail for insurance fraud because that's not what they'll pay. That's not what it's for, they'll say." In perceiving his insurance as a series of battles, Kevin gains more autonomy and less hassle by simply paying for his therapy out of pocket.

What does all of the above mean for the patient-client distinction at KP? First, it means that patients must go through regular evaluations that clients do not. While clients like Kevin desire this lack of oversight, others who attend rehabilitation at KP see this as a lack of care and permission to not offer equivalent service to all equitably. For instance, Pamela, the mother of a woman with TBI (which renders her nonverbal), explained one day out of frustration how, "They document everything for people on insurance. But for others like my daughter, they don't have any record of that. Look, they only have one person working with her right now, versus people like [another patient] who have two. I don't think that's right." Because self-pay clients have sessions with trainers and insurance-covered patients have sessions with licensed physical therapists, those who come to KP quickly identify who is insured and who is not.

Furthermore, in Pamela's frustration, she touched on a truism: that patients require much more oversight and documentation than self-pay clients. Patients must track their sessions to make sure that each one will be covered, otherwise they risk having to pay for sessions out of pocket. While documentation for all is performed through S.O.A.P. notes (with categories covering subjective experiences, objective indicators, assessment of a patient/client, and plans for future care), documentation for clients by trainers is typically less than half a page long while documentation for patients by therapists is anywhere from 2-4 full pages.

Carmen explains that "compliance" with Medicare and insurance "can be somewhat challenging." "The notes we write, and the format are different than what the trainers do. Trainers have a blank box that they fill in, but physical therapists work on objectives, justify

quantities, and have to worry about compliance.” She explains how, if she words things the wrong way, then insurance may decline to pay for a patients’ session. As such, insurance is tied to qualifications, medical billing, and whether a person can continue to pursue therapy, which many at KP deem as necessary for their overall health and well-being. However, the kind of active stance that ABT at KP prioritizes, while being partially shaped by Medicare qualification and requirements yet buffered by its donor structure, also shapes the kinds of ethical lives clients and patients at KP believe they should construct for themselves.

Structural Anthropology: The Moral Project of Living with SCI

Every society is at once rational and irrational. They are necessarily rational in their mechanisms, their gears and wheels, their systems of connection, and even by virtue of the place they assign to the irrational. All this presupposes, however, codes or axioms which do not result by chance, but which do not have an intrinsic rationality either. It's just like theology: everything about it is quite rational if you accept sin, the immaculate conception, and the incarnation. Reason is always a region carved out of the irrational—not sheltered from the irrational at all, but traversed by it and only defined by a particular kind of relationship among irrational factors. Underneath all reason lies delirium, and drift. Everything about capitalism is rational, except capital or capitalism.

- Gilles Deleuze (2003, 262)

A major turn in anthropological theorizing upended simplistic binary categories in favor of understanding their rational processes. In this dissertation, I use a different definition of “rational” – rather than implying some logical inclination towards objectivity, I define rational/ity as a set of practices, activities, or identities that are intelligible and consonant within a symbolic system. Given this, Claude Levi-Strauss’ structuralism is used here for its attention to how many of these patterns and structures remain so normalized so as to be hidden from conscious expression and awareness (Levi-Strauss 1967, 273-274). Levi-Strauss (1966, 58) argued that the mind has inherent constraints, and that anthropologists could utilize this structure

in order to understand symbols and their connections. How do we do this? Only “by making a minute study of how they work through different channels in the particular ideology of many different cultures” (Levi-Strauss 1972, 10).

In a structural analysis, this entails investigating how symbols are formed and how we conceive of their relational forces, which are often expressed through binary oppositions. These may also be defined as *cultural paradigms*, in which “human action in the world is to be understood as mediated by cultural design, which gives order at once to practical experience, customary practices, and the relationship between the two” (Sahlins 1976, 55). In other words, to normalized categories and the practical everyday life. Thus, the literature above on audit culture intersects with anthropological analyses of governmentality, which sees the normative gaze as “a surveillance that makes it possible to qualify, to classify and to punish. It establishes over individuals a visibility through which one differentiates them and judges them” (Foucault 1979, 184). As such, anthropologists have elaborated how private acts are never so disconnected from national interests (Kanaanah 2002), with dis/empowerment signaling a “stratified reproduction” (Colen 1986; Ginsburg and Rapp 1995). Yet, by separating these normative narratives from normative practices, this dissertation juxtaposes higher order explicit explanations from unconscious implicit ethical modalities.

This is relevant since, at KP, many of the normative narratives communicated by staff and patients/clients are presented in contested, oppositional ways. As briefly discussed at the end of Chapter 4, KP conducts long-term versus short-term rehabilitation; its strategies are total body opposed to localized; relational opposed to bureaucratic; and hopeful opposed to hopeless. Rather than being due to some fundamental, universal human cognitive structure per se, much of cultural identity is often created through “creative refusal,” where there is a “conscious rejection”

of an established, accepted, and somewhat hegemonic paradigm (Graeber 2013b, 1). In other words, much of cultural/group self-identity can often be predicated on whom one is not. In this case, at KP, being an ABT therapy center opposed to a traditional, 45-minute therapy modality. What this implies for the oppositional narratives at KP is that it defines its operations in opposition to “traditional” therapeutic practice, and it prioritizes resilience, an inherent part of *activity*-based therapy, over passive acceptance.

Maintaining The Active Stance

The very first ABT center was established in 1999: Project Walk, an outpatient rehabilitation center in Carlsbad, California (Jones et al. 2012). Project Walk was founded by Ted Dardzinski, who created the “Dardzinski Method” (Dardzinski 2022), which Daniel, KP’s lead trainer who first gained experience in ABT for pwSCI at Project Walk Orland, describes as

Basically, the same as a progression of a baby. From rolling-- rolling from back to stomach, stomach to back, getting on all fours, being able to balance on all fours, being able to sit up. And then being able to do locomotor. So, a lot of the progression comes from something like that, and then just adding on expanding on how to make all those aspects stronger. So that's why you'll see a lot of our guys get on hands and knees. You see a lot of our guys standing. You see a lot of guys learning how to roll because a lot of that comes from just the progressive method of: “How did a baby learn how to walk?” type thing, and then just applying it to an adult because we have to relearn how to do that stuff. So that method’s already kind of in place. It's kind of like a muscle memory type thing. They- they had it back then, and because they lost it, we need to retrain and do some of the same things here.

This method was integrated at KP due to Daniel having interned at Project Walk Orlando. Daniel was one of the first individuals employed at KP where he was tasked with replicating the kind of ABT instituted at Project Walk Orlando, where Daniel and KP’s founder first met, and where they each first became acquainted with ABT. For ABT at KP, the Dardzinski Method forms

another layer of “truth” – it conceptualizes the body in a way so as to make therapy procedures and logics more rational, straightforward, and productive.

The rationale of ABT is that there is still a progression, in which individuals can relearn and retrain their bodies to remember tasks and motor functions that it might have lost. These can be recouped to some degree. Daniel explains that the process of ABT at KP believes that there is always a benefit to this kind of active therapy, because whether physical functioning can be recouped or if it simply maintains a body’s functions (in the chance that a “cure” is discovered), ABT is the best one can do for oneself: Without therapy, patients:

Definitely have a higher chance of hurting themselves. You know what I mean? So, if their balance isn't there, they're not going to be able to stand up. If that bone density or muscle tone and their lower extremities isn't there, they're not going to be able to stand up, so then the hope is there already, and they know it works. But now you're still taking away their hope because you weren't doing the proper care, you know, prior.

In explaining the utility of therapy, Daniel argues that there is no drawback to ABT. In fact, it is the most hopeful kind of therapy because it offers the best maintenance for a body to be able to one day walk, and it offers the best chance at recovery through therapy itself. “We're hoping something's going to make these guys walk again. Whether it's now whether it's 10 years from now 20 years from now, but you have to adopt this kind of lifestyle, so that they're ready for it.”

This stance about the kind of therapy offered at KP was echoed by all staff members. Carmen explains how, “I don’t understand what [Tom’s doctor] meant by that,” explaining that Tom’s doctor’s recommendation (detailed in the last chapter) that he stop doing ABT at KP as it was “high risk” was incorrect as, “it still helps with circulation, bone density, and overall health.” Similarly, Diana wonders if “a lot of these people have zero faith in the health care system because they've been put in a box by what they might be able to do.”

As Jack explains, using Jessica as an example,

When she first got here, we had to Hoyer lift her out of her electric chair to the mat you know and then over time, you know she was like “Oh, well, I want to progress to a manual chair,” so then we, you know, we work on her sitting. We work on her arm strength, so that she can push herself, and you know what I mean. Okay, “I want to be able to try- I want to do slide board transfers,” so, then you start, and you break that down. Okay, so we start with scooting on the [transfer] board just left and right down the edge of the table and back, trying to get her to be able to scoot over all of that and then like, break that down. Now it's like, okay, now we've got to be able to lean. You have to lean on your arms without your- without your arm giving out so that you can put- you can shift the weight and then you'll be able to scoot yourself. And then you've got to tie all that, together.

For Jack, Jessica and patients like her are the proof that this kind of therapy works. Every day, these incremental progressions prove the neuroplasticity inherent in SCI patients. “She's come a really long way, you know what I mean and it's amazing to see.”

Jack goes further, describing how,

New therapists come in here and they're like “Okay, we're going to do three sets of 10 of ball squeezes,” and you're like “No, they can't,” you know what I mean? So, you have to- You have to get creative and help them to use the muscles that they have. And then kind of work your way from there. So, you have to get out of the ortho mindset.

Much of ABT is about learning a new mode of therapy that is total body, incremental, and long-term. Unlike “ortho,” short for orthopedics (concerned with the musculoskeletal opposed to neurological system), which is localized to certain parts of the body and involves simply strengthening parts of the body. However, at other facilities, “the main focus on therapy is like, okay here's some bed mobility and here you know wound care. Wound prevention, and this and that, and then it's like ‘Okay enjoy your new life,’ you know?”

This touches on a core difference between these therapies: one is focused on how to live with an injury while the other is focused on possibilities that may still be achievable – even if this involves small, incremental progression. Diana, a PTA at KP, currently works another job at a hospital rehabilitation facility, stating that this further reinforces these differences. She states

that “In a traditional physical therapy sense, short term goals for typical physical therapy are like two-week goals. In here that's just not a not a reasonable timeline.” This helps clarify the difference in purpose between such facilities. At KP, which sees 55 of the same clients over long periods of time, rehabilitation is long-term and persistent. At a facility like the local hospital, which specializes in sudden, traumatic, and acute care, it needs to serve thousands of patients in rapid, short-term succession. Indeed, the patients at KP who received therapies at the local hospital (Jessica, Caleb, Sam, and Paul) did so when their injuries were new.

What does this mean for these different therapy modalities? Carolyn Rouse (2009, xi) argues that “One can often trace the justification for a particular treatment decision to a resource constraint.” Considering this, I hypothesize that contentious statements, as stated by the VA researcher in Chapter 4, that “Medicine has shown that doing these exercises daily doesn’t have a huge benefit... but I am interested in some of these divergent modes of care,” while not aligning with some research on functional mobility and rehabilitation, does align with organizational rationalities. This statement is rational according to a system like the VA, which is concerned with increasing its capacity to care for the astounding number of patients that cycle through its clinics. Instead, we see that the kinds of rationalizations spoken by all interlocutors inhabit different ontological spaces because of their different governmental rationalities.

I cannot accurately represent the VA system here, as I spoke with very few VA-affiliated individuals during this research. However, in seeking to capture the kinds of sentiments that the VA system inspires in patients at KP, there is clearly a negotiation between what is communicated to clients, and how that seems to conflict with KP’s own systems. Most relevantly, it is the debate on whether therapy is effective and useful, which is quite significant. On one level, it indicates that despite the *Jimmo* decision, the idea that therapy can promote

health is still not accepted. Perhaps it will take years or decades for that decision's effects to shift the existing governmentality for large SCI care institutions.

To fully illustrate this point, I'd like to describe the situation of Lucas, a veteran who was diagnosed with a "diffuse TBI" in 2004, when he was involved in a military vehicle being overturned when he was on deployment. While not having a SCI per se, his involvement at KP is relevant for how therapy is performed on those with relatively low level of functioning. Lucas is nonverbal, but interacts with KP staff through gestures, smiles, and 'daps.' About three weeks after first meeting Lucas, I first heard a phrase that would be repeated over and over again to describe people like Lucas: that they were engaged in 'passive sessions.' This was first used by Jerome, one of the trainers at KP, but would be repeated by Daniel and even Carmen. Due to the severity of his injury, it was understood that Lucas' therapy would entail specifically tailoring movements and exercises that would be challenging for him.

Lucas' sessions consist of having him roll on his stomach – which involves KP staff first situating his body (torso, legs, and arms) into the optimal position, and then prompting him to roll over on his own. As Daniel explains, "Since he spends most of his time in his chair or in bed on his back, we get him on his stomach and have him lie there for a while, and we ask him to lift his head as much as possible." Indeed, with every request to, "Lift your head up, Lucas," he complies, but tends to relax after about a minute of engagement.

Another main exercise Lucas performs is where a machine allows him to pedal with his arms. There are a few mechanisms that would enable this: one is a functional electrical stimulation (FES) bike, the other is a non-electric bike with pedals attached to it. Lucas is placed on the non-electrical machine where he is strapped in and asked to move his arms. He is assisted by trainers as he "has limited range of motion," per Daniel. Indeed, Lucas' arms and limbs have

some significant contractures that KP staff assure me “used to be a lot worse before he started coming here.” As Daniel explains, “Lucas mainly needs stretching because whatever happened 17 years ago was not addressed fast enough.” For many pwSCI and TBI patients, lack of movement and stretching in arms and legs can lead to significant shortening of muscles and tendons that forces their body to tighten up and their limbs to curl.

Despite being nonverbal, trainers like Daniel and Jerome, who are the two trainers that primarily work with Lucas, regularly chat with him, making comments about KP or popular media. Lucas also provides enough feedback to affect his interactions with KP’s trainers, where they ask him if the stretch he feels in his arm is “Good? No good, too much?” Even these “passive sessions” are engaged. They still embody the ethical modality of KP. While Daniel explains that “neuro is so vast and different from person to person,” for each person, their goals are to “build up functional mobility based on where they are at with their own bodies.” This translates, for Lucas, into enabling even the most basic movements, if that is all a person can perform.

It is invariably understood at KP that the conditions present there are each unique and capable of some form of recovery, no matter how incremental it might be. All staff members held this to be true. However, this is most relevant to PT, PTA, and intern members who cycled through KP, as all of these have theoretically had training in exactly how to conduct this work. As indicated by Diana, “in [PTA] school, there is just one 5-and-a-half-week class on everything neuro. But nothing in the textbooks actually work. And plus, there’s not a lot of clinical research on spinal cord injury because of the diversity. For something like cancer, it varies, but you can get categorized pretty well, but SCI is not at that level yet.” Similarly, Jared states that “school gave me some fundamentals, like basic PT rehab, but here I had to learn activity-based therapy,”

explaining that much of what needed to be learned was not accounted for in his training and education.

Carmen's comments clarify exactly what is meant here. Rather than training being inadequate, she asserts that the main difference is in expectations. "Progress looks small for this population. And small gains may not necessarily transfer to better outcomes. So, it may not seem like improving on paper. I can say they went from needing moderate to minimal help, and it can look like they haven't improved, but they have." Indeed, Diana argues that at KP, "the physical therapists have the understanding and education to be able to describe how or why certain exercises work." She explains that for SCI patients, "even though traditional therapy tries to strengthen all components, bodies here are different. Breaking down a movement doesn't mean that it will translate into [improvement]."

Which is it? Is training inadequate? Or are the expectations instilled by a given education (which may be a part of a hidden curriculum in PT training) really the issue? The latter seems most likely. As indicated by Diana, PT education gives KP's staff a knowledge base in order to communicate patient conditions and improvements in clinical terms. However, this training may instill some faulty expectations. This is exemplified by Jane, an intern attending a PTA school which requires she attend some clinical hours as a part of her training. Her time at KP fulfills this requirement.

Jane explains,

In our class we learned like a, you know, C7 spinal cord patient should present like this. Or C5 kind of patient, or whatever should present like this. You come here and there's, you know, a couple of different C5 injuries and they all present differently. And nothing like what the textbook says. So, you really have to, you know, think about each patient individually and not what their condition actually is. But obviously when I go take my boards, I have to go think about it as the textbook. So that's a little bit tricky. But definitely seeing it makes a lot more sense.

The fascinating phenomenon of translation from theory to practice is presented here. For Jane, the textbook must be intelligently communicated throughout her program, culminating in her ability to understand this process presented by being able to repeat these lessons through her board exams.

While resulting in her licensing and certifications, it also replicates an inherently inadequate understanding of SCI. What she has witnessed at KP “is so different from what I learned. The patients here present differently.” The anthropology of expertise is relevant here, as it investigates the subjecthood of a person deemed “expert,” who “has developed skills in, semiotic-epistemic competence for, and attentional concern with, some sphere of practical activity” (Boyer 2008, 39). Thus, experts are such not solely because they can deconstruct their field, but also because they are competent cultural actors.

This lens may also explain what Daniel, Jack, and Armando (another trainer) explained to me: that they have had issues with interns arriving and explicitly telling patients “You shouldn’t be able to do that.” In response, Daniel explains, “They know that already. That’s not how you’re going to be able to keep conversation with someone.” Diana explains that she understands this reaction from interns as, per their school training, “it’s like, ‘you’re doing stuff you shouldn’t be doing.’” However, at an ABT facility like KP, a part of learning expertise is learning how to navigate the world of human relationships, such as knowing more than what a textbook determines what is possible. KP’s staff have learned that (1) a textbook is too rigid to apply to bodies in the real world, and (2) that regardless, this is not information one should tell one’s patients and clients. Indeed, expertise involves being able to “finesse reality and animate evidence through mastery of verbal performance” (Matoesian 1999, 518).

This situation presents an unacknowledged conundrum for KP staff and its patients/clients. As discussed in the previous chapter, patients like Tom and Jessica, and Jamie (above), are presented with challenges that they have overcome despite doctors' prognoses that such goals are impossible. Yet, Jessica has gained the ability to transfer herself, Tom has gained significant control over his left arm (and as a result, increased independence), Jamie has some increased feeling and mobility in her legs, and KP staff like Jack, Diana, Daniel, and Carmen explain how inspired they are by such increased in ability. KP staff demonstrate how "expertise requires the mastery of verbal performance, including—perhaps most importantly—the ability to use language to index and therefore instantiate already existing inner states of knowledge" (Carr 2010, 19). In practice at KP, this structure of "hope," wherein ABT provides increased possibilities, is only made possible in tension with physician statements which KP staff contradict and recontextualize in light of patient and client progress narratives.

Put another way, physicians seem to create a tension that wouldn't exist otherwise. Is it possible that physicians lead patients to pursue therapy because patients regularly defy odds that doctors give them? Towards the tail end of this research, Carmen approached me with a question asking whether I asked patients about their goals and motivations for attending rehabilitation. She expressed that so many people want to walk again, despite it being very unlikely that they could. She stated that she will "never take that hope away" from them, but that she's "not sure" what her role should be.

As Carmen explained, and as described throughout this dissertation, many patients have stories about overcoming certain limitations their doctors gave them, and now it's as if they believe that all is possible as, as Carmen explains, "because if they were wrong about that, then they could be wrong about everything." Her inquiry expresses concern about the level of hope

provided. Without the amount of pushback patients receive from their physicians, would they place so much stock in the gains they experience at KP? In other words, the issue is that these low odds of recovery provided by physicians may have been erroneous to begin with. Is it possible that patients engage with this rational system more than they engage with how neuroplasticity actually functions within their bodies? I return to this issue in Chapter 6 as I outline how “hope” can be construed as a biocultural process rather than a mental attribute.

Discussion

This chapter introduced the structure of care at KP. I began by introducing Jamie, whose status as a fully disabled veteran by the VA enables her sessions at KP to be fully covered by her Tricare insurance. I argued that the logic of care at KP, that is, its rehabilitation and therapy sessions, ultimately conformed to the logic of Medicare billing (the primary insurance to which KP’s billing person and physical therapists must attend), using the session with Steven and Armando as an example. In addition, I outlined the moral sentiments surrounding non-profit, ABT care work, which at KP is supported by a donor structure where self-pay clients receive price reductions the more sessions they attend.

I then explained how clients see insurance as a frustrating process, with some opting to either self-pay, or to use insurances that operate in ways that make more sense for them, given SCI being a relatively expensive condition to live with. I then explain the social structure at KP, where its staff and rehab participants describe it contra “regular” or “traditional” rehabilitation. From interns to its senior staff, all at KP describe the gap between clinical knowledge and real-world application, explaining the utility of knowledge, and how it must be applied in an adept fashion by its professional staff. I hinted at a hidden curriculum, explaining that the expectations

such training provides (that creates barriers to what a person “should” be capable of) often runs counter to what staff confront on the therapy floor.

I also outlined the logics of the Dardzinski Method, and how it along with Medicare requirements and the structural categories deployed at KP all serve to structure care there. In other words, the interaction of all of these structures, including KP’s nonprofit donor-supported structure, all help illustrate how it came to be. I end by inquiring as to whether the image of disability taught to health professionals (and what one “should not be able to do”) was ever valid to begin with – if not, then patients and clients may be forced to take on a struggle for neuroplastic regeneration (of which they’re not “supposed” to be able to do) based on moral claims rather than objective, physical ones.

This chapter has provided a description forming a basis for delving deeper into chapter 6, where I the kinds of affects that circulate around KP. This focus provides scaffolding for the discussion on hope as a biocultural (social, political, and emotional) process. It also helps outline the sentiments and cultural dynamics at play at KP, which helps illuminate how “walking again” as a goal is reinforced in pwSCI’s lives, and how/why KP staff attempt to moderate such expectations in their patients/clients in ways that support and motivate their rehab participants that are culturally relevant given KP’s ethos. Despite the optimism with which patients and clients receive such proscriptions, I argue that its similarity to physicians’ proscriptions illuminates the ethical stance of “hope” in which patients and clients operate: object-oriented versus process-oriented ontologies of hope.

Chapter Six: Ethical Affects: Or, Learning How to Become Paralyzed

As previously established, in SCI care there exists a double bind wherein patients are granted moral, transcendental possibilities while also being expected to “do nothing.” These individual dimensions simultaneously exist within governmentalities which not only function through restrictive mechanisms but are often rationalized in ways that effectively create compliance amongst patients. Above, I described how insurance logics and care recommendations from physicians and others operate according to a governmentality wherein prevention of patient risk of injury is prioritized.

In this chapter, I further illustrate the techniques and rational systems instituted by rehabilitation staff in order to situate certain statements and actions within their proper ethical affective worlds – where rehabilitation professionals and patients negotiate this ethic. This helps to make sense of physician recommendations and prognoses which pwSCI at times experience as harsh utterances that take away any hopes of recovery. This chapter focuses on ethical affects – the tacit and naturalized feelings that emerge in ethnographic text as a result of a temporal continuity. This is opposed to moral judgments and emotions, which emerge after the fact of analysis and social impositions.

While ethical affects are also by definition culturally molded, their temporality is omnipresent, requiring deeper considerations than the structural anthropological analyses used in the last chapter. There, the utility of binary oppositions was useful for outlining the kinds of images of thought that we dogmatically internalize and reinforce – such as “us versus them” types of relationships. However, the ethnographic events themselves involve much more

ambiguity and can reveal the unconscious ethical structures that determine the kinds of activities, reactions, and feelings deemed appropriate in human social and personal life; that is, in living with each other and on our own terms. Sociality at KP is thus also centered in this chapter. Below, I reintroduce patients such as Tom, James, and Jessica, as well as clients such as Veronica, Kevin, and Caleb. These individuals' experiences and ethical stances are placed in conversation with KP staff in order to provide a comprehensive view of the sentiments that circulate around KP. Specifically, not only are there moral standards communicated through moral values (including emotional appeals), but also, there are implicit ethical norms (the organic, affective reactions that indicate a "beyond" to such rigid categories). These emerge from ethnographic data below.

I start from the explicit, moral communication, opening a door for the more tacit, affective level, which "are immanent, obtuse, and erratic, in contrast to the 'obvious meaning' of semantic message and symbolic signification" (Stewart 2007, 3). Distinguishing between what is communicated and what is lived is valuable for outlining how ethical affects function at KP. To do this, I zero in on (1) the transcendental moral ideals communicated by KP staff and pwSCI there, which assert what a "good life" entails; next, this is illustrated through an expression of (2) the kinds of jokes told at KP and the role they play in a KP sociality; and these culminate in the elaboration of (3) the cohesive cultural outlook at KP as indicated by both what interlocutors said as well as how therapeutic practice is conducted. The result is understanding *how* certain statements and claims are situated in order to properly contextualize them.

How to Live the Good Life

A valuable part of SCI is learning a new means of social relabeling. That is, learning how to enact a new subject position where a person "learns to be," for instance, "the kind of leper his

family and neighbors, even his doctors, expect him to be” (Waxler 2016, 236). Part of this process of learning to be a certain kind of pwSCI also takes place amongst KP’s staff, who are also affected by SCI’s debilitation. As stated by Jack,

Every day I come here is a reminder of what I take for granted, just being able to get up and go to the bathroom in the morning when I get out of bed. You know what I mean? Like, it's just like- you know, we tend to complain about problems: “oh man my rent’s due,” “the bills.” “Oh, I need to fix this.” “Oh, I need to do that.” Whining. We whine. We're a bunch of bitches right. And then you come here and you're like man I don't have any problems, really, you know what I mean? So, it's definitely a real-- every day is a reality check.

Different from Chapter 4 where Jessica discusses how SCI is such a transcendent condition that she would not wish it on her worst enemy, here, Jack describes SCI patients with which he works as reorienting his own stance to life. Their situations are undeniably difficult compared to anything he might encounter in his day-to-day because at least he still has his abilities and faculties. “My own issues that I complain about for the first five minutes of the day, as soon as I come here, none of that shit matters. Perspective. People have different problems.”

Similarly, PTA Jared describes how it is “inspiring seeing [patients] try for goals.” In fact, he describes how dealing with patients with such intense injuries, and who have lost control of significant parts of their bodies, has forced him to consider that “in the grand scheme of things, it's really nothing compared to what some of these people have to deal with and have gone through.” Despite these hardships, pwSCI at KP learn specific ways of living a “good” life, which is laden with moral implications. This ethical approach to life reflects what Cheryl Mattingly (2018) calls immanent transcendence, where we strive for doing the best good we can in the midst of life’s most dire circumstances. This ethical standpoint, though, far from being some generalizable universal, is a given cultural perspective/value that becomes more reinforced through a given political economic arrangement. In this case, how SCI inhabits an extra/ordinary,

transcendent space in US culture, where, even though it is the best good relative to others, a debility in the body is concomitant with a socially dislocated affect – e.g., where individuals are given certain resources as well as an expectation to be unable to recover bodily functions. One way of understanding what this entails is by paying attention to how some participants at KP describe striving for a better life.

In considering how to live a “better” life, Tom describes a tension between thinking a cure for SCI would make his injury “for nothing,” while also feeling like “If this is how I have to live the rest of my life, I wouldn’t want to live that long.” Nevertheless, Tom maintains hope for how he can help improve access for people with disabilities in public spaces. Tom’s father, Tom Sr., explains how they took a road trip around the U.S., being surprised at how, while “our state parks have a long way to go,” “a lot of accessible [spaces were] really on Indian reservations,” which were the only areas around the Grand Canyon that they could take buses to access tourist hotspots. Tom points to KP’s founder, Randy, as a model for what he would like to accomplish in the world for people with injuries and conditions like his. He states that he would “like to help people like me.”

Tom’s desire for a larger purpose likely stems from several affective sources, such as the situation that brought about his injury. While serving in Afghanistan during Operation Enduring Freedom, Tom sat in a truck with three other soldiers who all died in the explosion that debilitated him. While he didn’t have strong bonds with these men, he expressed sadness for them all, but particularly the one whose daughter was born just five days earlier, explaining that, without a wife or children, he himself “should probably be one of the ones that shouldn’t have survived.” However, when considering how he now engages in the world, Tom explains that he no longer “feels emotions,” and that “being emotional since injury” is “a challenge for sure.”

Despite claiming to “no longer feel emotions,” Tom also feels obliged to help those also in this condition, and to honor those who were killed in his attack. Tom has a tattoo on his right shoulder with these men’s names inscribed on dog tags, commemorating their deaths.

What does it mean to not “feel emotions”? Is this some absolute reality/position? Or is it a social ontology: one where Tom explains that feeling emotions may cause him to “forget”? Thus, he doesn’t “deserve” for those emotions to leave him. Yet, Tom also communicates concern that he “might never stop” if he did allow himself to feel those emotions. We see a robust phenomenology emerge from Tom’s descriptions, but I suggest that they stem from different regimes of truth in which he is invested – the immanent extra/ordinary double bind ascribed to pwSCI such as Tom.

First, Tom experiences daily how his injury manifests difficulties in navigating the world. “This world wasn’t meant for paralyzed people... being like this, you see people’s true colors,” which he describes in cases where people insult him based on his injury. Tom explains, “I sometimes enjoy when people tell me something douchey. I can respect your insult... but I’m just impressed with new jokes. Most para- jokes are repeated all the time.” “When this happens, I can let one comment ruin my day, or take it, laugh, and go about my business.” In terms of accessibility, Tom explains how “sidewalks without a lip or a ramp, small bathrooms, narrow doors, carpets” are all difficult to travel when in a wheelchair. Some spaces de facto exclude paralyzed individuals. Thus, Tom’s desire to change the world and make it “meant for paralyzed people” stems from these *ordinary* daily experiences.

Second, Tom inhabits an *extraordinary* space where he is able to be insulted on account of his disability. In another sense, individuals suggest he “share my story” and “make a difference” for this community. The belief here seems to indicate a power to propel change in a

manner that few can achieve. Yet, such a belief illuminates Tom's social dislocation. He is tasked with a duty that his disability enables, which may obscure how other opportunities may end up cut off as a result.

Third, and most relevant to Tom's emotionality, is how Tom's guilt is mediated by moral judgments about who should have survived and why. As stated above, this immanent transcendence is a situated value that is reinforced through social arrangements. In Tom's case, how SCI inhabits an extra/ordinary, transcendent space in US culture, where even though it is the best good relative to others (Tom was the only one to survive), a debility in his body is concomitant with a socially debilitated affect where Tom has little guidance on how to deal with such death and trauma. Thus, it is more likely that Tom emotes *differently* rather than not at all. Tom's social dislocation is visible in how he is still learning how to be the kind of pwSCI that others expect him to be.

What kind of pwSCI do KP staff expect Tom to be? KP staff, while desiring not to "take away" clients' and patients' hopes, still recommend a level of acceptance of their situation. As Diana states: "at the end of the day, this is a long-term condition, and if you can't ever come to terms with that, it's not going to be very healthy and you're not going to live your life to the fullest because you're going to always feel like something is missing, when you can have a full happy life. You should strive for that, no matter what your circumstances, everybody should." The negotiation between acceptance and struggle is inherently unclear.

Throughout this research, I have struggled to understand the true difference between physician recommendations and those of KP staff. For instance, in Chapter 4 I argued that "hope" interplays with how one's body is defined has having a certain level of recovery potential, leaving those evaluated as having less potential somewhat abandoned in their pursuit to

recoup physical functioning. Yet, as discussed in Chapter 5, as Carmen explains, KP staff also hope to move rehab participants away from a relentless focus on recovery to leave room for doubt and, thus, more staff-directed therapies rather than hope-directed ones.

Each, to some degree, recommends that patients accept their situation as it improves all outcomes. Physicians such as Tom's explain that some risks are not worth taking for the wrong reasons – that is, if they wish to walk again, then that is problematic as it is unrealistic. KP staff explain, more pragmatically, how this issue matters. On the one hand, it is less about walking again than it is about overall well-being. As Carmen states, “it still helps with circulation, bone density, and overall health.” On the other hand, in rehabilitation sessions, patients may want to do something like practice their walking because that is their primary, singular goal. PTA Jared tells me this can be difficult because those patients may not have much core strength, for example. And so, hope for walking can motivate them to practice walking, thereby detracting from the next feasible step that patients would derive more benefits from, such as core exercises that are more targeted and incremental.

Jack describes KP participants, stating that, “when [an injury] first happens and they're first trying to understand like what's happening here, it's like, they're still trying to wrap their head around like, how long forever is, you know what I mean? And that's very difficult.” And so:

You take somebody that is fresh injured and, like every little piece of- of progress, they make is like "look I moved my toe by myself," you know "for like five times." And they're like all excited about it and you don't want to take their hope away right. I mean- and so you're like "Fuck yeah that's awesome dude." But then you look over [another] guy like Kevin and he's like at the next table, who he's been paralyzed for six, eight years already, and- and he has different goals. Because, like the beginning, like the new injury, their whole thing is "I'm going to walk again," "I'm going to climb up," "I'm going to get back to work," "I'm going to be climbing power poles again," "I'm going to be this," "I'm going to be that," right... compare that to Kevin, who is like you know, eight years in and

his goals are totally different now. He's accepted it. There's an excited- it's like the Kubler Ross thing man, it's like the stages of death and dying.

As discussed in previous chapters, some of the messaging about their *incapabilities* gets questioned at the KP moral laboratory, where they see first-hand (and for the first time with/in their bodies) what they are capable of. Thus, it takes patients and clients re-learning how to create a new set of expectations entirely separate from physician diagnoses and prognoses as well as the optimism of which Jack speaks.

Using Kevin as an example, Jack explains how goals change over time, and it is not their role to control that process, except regarding how it impacts the progression of therapy. As Daniel explains, “A lot of the older patients that have been coming through the years are more have- maybe are more accepting of their injury. So, you know they haven't seen any movement in their legs, or they haven't seen any other functions below their injury, so they are more accepting of the fact that, you know, ‘maybe I'm not going to walk again.’ But I've never taken away that hope.” KP staff negotiate productive therapies, as Jared explained above, where their training determines what would help increase independence, physical functioning, and strength. At times, a patients’ eagerness to pursue exercises like walking may detract from these goals, and in these cases, patients who accept, to some extent, that they may never walk again, are more open to allowing KP staff to guide their sessions. In other words, to institute good care, patients may need to relinquish some control over ultimate outcomes of their conditions.

To what extent is the goal still, like the perspectives of physicians and biomedical professionals, pushing for patient compliance? Howard Stein (1990) argues that biomedicine is less about helping through objective treatments, and more about compulsively changing patients in order to prove one’s ability to heal. This tension creates a dichotomy of active versus passive – where the active, physician “doer” “takes charge” of a patient, resisting the dangers of passivity,

and where the patients are obligated to use socially acceptable avenues “in order to become an active member of society” again (Stein 1990, 31).

At KP, staff and participants engage with one another for continuous 2-hour sessions, multiple times per week. Naturally, patients and clients come to know those who attend rehabilitation sessions during their same time slots, as they often see these same individuals weekly. Given such sociality, what do individuals receive at KP? I argue that they receive *culturally relevant interactions* – in which the cultural milieu dominant at KP concerns active and rugged exercises, such as lifting weights, running, and hiking, as well as activities such as mixed martial arts, jiu jitsu, rock climbing, and mountain biking. For example, KP participants like Sam, Veronica, Caleb, Jessica, and James, among many others, describe their lives before injury as very active. For instance, Sam was injured during a mountain biking accident, and defines a satisfactory endpoint as one where “I can go back to being as active as I was.” A pre- to post-injury continuity is said to exist where, as Jack explains, “who you were before your injury plays a part.” Or as Katie, KP’s operations manager explains, how a person deals with their injury “has less to do with that injury and more with who you were.”

This sentiment is echoed by Kevin, who explains, “I don’t understand depression at all. I’ve always had a positive way of looking at everything. When I was younger, up to my wild shit, I waited 3 days in jail for the judge, and I enjoyed it.” Kevin, discussed in the last chapter, was injured eleven years ago while on the job working construction at the age of 54. He fell about 10 feet, directly on his head after a safety rail failed. While Kevin recalls the injury, and instructing his co-workers about how he broke his neck and could not move, he recalls being so “filled with drugs after my surgery [that] I lost some memory.” He was diagnosed with a C4/C5 complete injury. Despite his injury, Kevin described still having a full schedule, including

attending weekly sessions of Narcotics Anonymous and Alcoholics Anonymous. His history of addiction is what motivates him to stay completely away from any kind of medication that he deems unnecessary and risky. Kevin describes his history of drug use as “I can’t just eat one Oreo.”

This notion of a persistent identity is also echoed by Jessica, who, prior to her injury was practicing jiu jitsu and was preparing for her first tournament. At KP, Jessica tells Jack, “I’ll be your guinea pig, I’m up for anything.” At KP, Jessica tells me that she is “down to try anything that could help me walk again” including a pair of virtual reality goggles that KP’s patients and clients can utilize during their therapy. During our first interview, Jessica tells me that, coming to KP every day, she will “usually say ‘whatever I’m game,’ you know because I like being the guinea pig. You got something new? Let’s try it.” Jessica describes herself as adventurous and active, even expressing interest in continuing jiu jitsu lessons once she gains enough confidence in her body.

Another client at KP, Sam, was injured in a mountain biking accident two years ago at age 56 where he explains that he didn’t “ride the drop well,” and was airlifted to University of Virginia (UVA) medical center. He was designated a T12 complete injury at the time. He is now designated as a L1 incomplete injury. When asked about his goals at KP, Sam explains that “everybody’s goal here is to walk again.” Despite his debility, he states that he has a “stronger upper body than ever.” Sam explains that “every day is the same,” but he has learned to navigate his life differently than he did before. This is how he has been able to overcome any challenges that living in a wheelchair has brought. While he sees “posts on Facebook showing all of these people in shit situations,” he thinks that “people are their own limitations.”

Sam points to Caleb as inspirational, as “that kid gives 1000% every day. That kid could be the most bitter, but he chooses not to. He doesn’t do the ‘woe is me’ bullshit. But all of that comes down to the person.” Here, we see the notion of who one is (regardless of injury) emerge as well as how one ought to live, where a “woe is me” attitude is “bullshit.” Yet, regarding life’s challenges, Sam explains that “This life is expensive, and the system doesn’t support it.” Despite this, hardships are “no excuse.” “Abled people have shitty days, too.”

One important role KP fills in Sam’s life is as “a social event where we can have some fun. But the exercise makes it good physically. There’s no point where I won’t need PT anymore. I look forward to going there.” Sam communicates the value of “not complaining,” not being, as Jack stated, “a bunch of bitches,” and even keeping strong and staying positive, like Kevin recommends, and as an ethic that Sam feels that Caleb embodies. In addition, Sam explains that he “stays active,” “just like I was before my injury.”

One last individual that embodies this sentiment is Veronica, a TBI patient at KP who, while not having a SCI, communicates a sentiment pertinent to the sociality there. In fact, it is TBI patients like Veronica (like Lucas in the last chapter) whose experiences help illuminate the ethic at KP. Veronica is a 43-year-old woman who received a TBI six years prior when her ex-boyfriend broke a bottle on the back of her head during a dispute Veronica cannot recollect. While she does not remember the incident, he could often become abusive during their relationship. Police detectives have assured Veronica and her father that, while they believe the circumstantial evidence could prove that he attacked her – and that she didn’t simply fall, as he claimed – since Veronica has no memory of the event, pressing criminal charges would be unwise.

After her initial injury, Veronica was completely ambulatory and had minimal functional limitations. However, after her shunt (tubing inserted into her brain to drain accumulating fluids) became infected, she needed repeated surgeries (a total of ten) that resulted in significant limitations where she became wheelchair bound. Veronica's insurance covers physical therapy at many in-network facilities, none of which specialize in neurorehabilitation. And so, Veronica pays out-of-pocket to attend rehabilitation sessions at KP. While she and her father – her primary caretaker – can shoulder many costs, they have gotten ample support from a foundation that supports people who work in the film production industry, of which they are a part. While this foundation has given them much-needed assistance for the past 6 years, they will be unable to receive more assistance in the future.

Despite this, Veronica has experienced incredible benefits since she started receiving care at KP. Even though she “make[s] less than I did in high school,” Veronica will continue to pay out-of-pocket for therapy at KP which she credits for helping her develop the kind of functional independence she's been able to develop over the past three years since she started there. At 2 hours per session, Veronica spends about 4 hours working with her trainer every week. Veronica explains that KP serves as an extension of her support system – people who are invested in her recovery and well-being. KP also fosters the type of atmosphere – with Hip Hop, Rock, Metal, and other music genres playing in the background – and offers the kind of motivation and drive for patients and clients to succeed. KP, and activity-based therapy in general, caters to specific people like Veronica who were incredibly active before injury.

Veronica tells me how she used to exercise at least 6 days per week, doing “cross-fit and everything I possibly could to be moving and active.” What all of this indicates is that individuals need to be fit into a therapy modality that aligns with their own rituals that they find

intelligible. In this case, the kind of active sessions that one attributes to team- or gym-like settings. Indeed, Jessica, described earlier, does not refer to KP as “therapy,” but instead “I call it the gym, because that’s what it is.”

All of these patients and clients engage within a thick social space where sentiments are exchanged, and standards are shared. Standards such as staying strong and not “whining.” A social space of mutual support, where all at KP share a similar ethical outlook. I believe such social connections are important to this long-term mode of therapy and care. In addition, KP offers its patients and clients a space where they are capable of being affected by others in ways they rarely experience.

Transcendence as a Means of Being Affected

There is one more link I will make to the transcendental comments made by KP’s staff and participants. For instance: Jessica’s claim that SCI is something “I would not wish, I would not wish this on any of my enemies, you know? Even- even like the person that I just like- want to be gone. I would- I would not wish that on them because it's not something that you want to go through.” Similarly, Jack’s notion that “My own issues that I complain about for the first five minutes of the day, as soon as I come here, none of that shit matters. Perspective. People have different problems.” These comments are illuminated when placed in the perspective of affects – how we are affected, how we come to be affected, and what it means to be affected. I argue that such comparisons are the result of relations of intelligibility – *who*, in our lives, can affect us in particular ways?

This is illuminated by a story James told me:

We were at the Vet Games and a friend of mine, he does the Power Chair Rally, so I went to go see him at his Rally because, you know, we try to support each other while we’re there. So, um- I couldn’t sit because there were so many people- there was so many

people there- able bodies. So, I went around to where I could see him, but I was further away from him. His daughter seen me, so she waved, I waved. My wife was over there, near where he was at. So- but God put me right where I needed to be because there was a kid- young kid that was doing the same rally that was operating the wheelchair with his head. And I looked and I'm sitting there with my glasses on, my sunglasses, and I turned and I- I didn't worry about my friend Gino. I was watching this kid and you know I- looking at him I just started to cry, and I was like "yo, you could be so much worse. Your sit- that could be you right there." You know, "you could be sitting there not being able to move at all, you know operating your wheelchair." But he was out there still doing it. So, it was motivation to me.

Stories like this communicate what is immanent to Jack's, Jared's, Jessica's, and others' stories about those who "have it worse." At KP, a part of the moral economy is having the socially acceptable ability and bandwidth to "complain." The eminent example of most of my interlocutors was KP's founder, who has a C3 complete SCI. As Jack explains,

I always use Randy as an example because I'll be like, "look man, look at Randy, you know he wasn't- he wasn't asking for any of this, but if he wouldn't have gotten shot in the neck, this place would never be here," you know. Like look what- how that- Randy had to have that happen for Randy to go through what he went through in order for this clinic to start, in order for you to be here right now, you know what I mean? Like everything is a series of events that's falling together.

To be in a situation/state as Randy, and to still work and build up such an organization, grants one immeasurable respect at KP. To have validity "to do nothing," to be depressed, and to rise up anyways is deemed an admirable and desirable quality. Recognition of high injury individuals enables those with lower level ("lesser") injuries to persist, "Because if he can do it, then I have no excuse," as James explains. "The first vet games was like, I was in wheelchair heaven. Because everybody was in a wheelchair. 'James, you're not the only one.' And 'James you—that could be you.' It humbles you. Because it's uh- you could be worse off than you are now. 'So, you thought you had problems? Look at that guy. His problems are worse than you.' But he might have had a better attitude than I had." James has C6/C7 complete injury. He used to live in New Jersey, but explains, "Florida is more wheelchair friendly. It's sunny, and you're just

more motivated to do stuff. It has the Riverwalk and other activities.” James has “spent 28 years in a chair.” “We didn’t have any of this equipment 28 years ago.”

Kevin finds SCI as transcendental in a different way, stating:

Breaking my neck at 53, I’ve lived a whole life. But all them people that are young and injured. They don’t know how to associate with real life, the way you live it. You know they have a real life, but it’s not necessarily any concept of- I- I know one kid that came to KP being paralyzed from the neck down. He used to drive his chair. They had a joystick up underneath his chin and that’s how he drove his chair. Smart little young man. He wanted to go to college. He wanted to be a lawyer, all that kind of stuff. But his mom has her little boy for the rest of her life.

For Kevin, the tragedy of SCI is compounded by whether a person had a chance to live their life as a normal, regular, abled person. We also see a core theme emerge regarding seeing SCI as a devolution of functional mobility. Indeed, this is the logic of the Dardzinski Method, which sees bodily recovery in terms of recouping abilities in ways similar to the development of a human being: from infancy to adulthood. Rehabilitation seems to occur along the same axis. Seeing SCI as a worst-case scenario is also reflected in Tom’s claim that, “If this is how I have to live the rest of my life, I wouldn’t want to live that long.”

Despite much of the focus resting upon worst case scenarios and an unwanted debility, such statements also communicate an ability to be affected by others. I’ve made claims above about a “socially dislocated affect.” On the one hand, it means that individuals have to learn to situate their dependence on others differently. On the other hand, the ability to be in a relationship with others shifts immensely after SCI. For people like Tom, Kevin, and James, the ability to feel remorse, pity, or sorrow for another’s situation, more than anything, arrives as a jolt, such as the moment when James was brought to tears. After their injuries, KP participants describe a period of sorrow and loss, such as Jamie, who described her time in Alabama (right

after her injury) as one where she felt depressed, and where “accepting all of these changes has been hard.”

What does this mean for sociality at KP? I believe these data illuminate an element inherent in all social relationships: the ability to be affected by other people means being emotionally engaged and stirred by another’s situation. In other words, people at KP meet someone that shocks them, when they have been in a state of being incapable of being shocked – as they often themselves inhabit the worst imaginable situation possible. This is similar to how Throop and Zahavi (2020, 287) define the social life of empathy: “When oriented to another empathically, we experience the intensity, rhythm, and pitch at which another is living through a given embodied situation.” However, initial injury for pwSCI I encountered is fraught with a diminished ability to form such intensity – at least with those still living. For example, as discussed in Chapter 4, Tom experiences sympathy for those soldiers that died in the car explosion that resulted in his injury. However, those with higher level injuries are able to shake him as well.

Indeed, this recognition of another’s intense situation shakes my interlocutors out of, at least momentarily, the mindset/cognitive loop they had been trapped in: sorrow, despair, and self-pity. This is akin to Arthur and Joan Kleinman (1994, 710-711) and their argument for how “culture infolds into the body,” and “how bodily processes unfold into social space.” In their argument, collective and individual memory are tightly connected – bringing about a need for understanding how the inter/subjective are co-constituted. However, “When viewed as an intersubjective process, empathy is not only implicated in the experience of understanding another but also in the experience of being understood” (Throop and Zahavi 2020, 290).

As they elaborate, interactions are filled with active attempts to be understood and stay responsive to one another. I argue that for the pwSCI at KP with which I spoke, therapy is a way of both testing one's limits as well as a means of meeting others with experiences that culturally matter most as these are others who have been ensnared by the double bind of SCI – of being both normatively injured and extraordinarily defined through the culturality of normative ableism (Wool 2015). After all, “the expressive, moral, and experiential dimensions of empathy are consequently culturally shaped” (Throop and Zahavi 2020, 290), illuminating routes through which evaluative secondary level rational expressions interplay with the chronicity of the normative primary ethical affective dynamics in which pwSCI find themselves.

James explains how his life changed coming to a place like KP. Pointing out another client at KP, James explains that,

There's a guy that goes to KP, I call him “Angry Man.” Because to get there- I don't know what happened to him. But before I leave though, Will, I'll- I'm gonna speak with him. Because like I said, in my years I have seen so many people. I know the look. I know the look on their face. Look in the eyes and I don't even have to know you. Yeah. Angry. But the situation- eight times out of 10 we cause the situation. Like me, I was in a car accident so who- who caused the car accident? Even though the guy ran me off the road, but I, it was in the car accident. Anyway. Like I told them at the rehab, I said he needs to be around more handicapped people, and they were like “no I think,” I said “no trust me. He needs to be around more gimps.” I call us gimps.

James describes in depth this phenomenon of being around people capable of affecting him.

“You know gimps need to be around more gimps, then, because you just don't want to be that lonely on- sitting out there on the apple field. That can bring you down, that can get you depressed and make you angry and then you know, once you get around a couple more people like you, that understand your problems. Then, you know. Makes life a little easier.” Jessica mirrors this, explaining that she is a part of five online support communities and is a mentor to several pwSCI who she chats with regularly.

Kevin reflects this as well, stating that, “a girl asked on the Internet, one day, she said, ‘How do I teach my son to be a quadriplegic?’ I said ‘You don’t teach him, quadriplegics teach him. You need to find your spinal care support group or go to a bigger city where there’s people in wheelchairs... find some people that your son can hang around with and learn how to do this.’” For pwSCI, they are constantly given messages about the kind of pwSCI they ought to be, even implicitly. Kevin, James, and Jessica reflect on receiving these messages in relation with others in similar situations rather than solely from abled persons. This allows one to gain an alternative perspective.

As an example for why this might be advisable, in a casual conversation with Daniel (trainer and floor supervisor) and Patrick (a training aide), they discuss Randy’s situation quite explicitly:

Daniel: Yeah so, he’s getting his house built.

Patrick: Oh, that’s cool.

Daniel: Yeah, the Gary Sinese Foundation built him a whole house that’s decked out and has everything for him to move around in his wheelchair.

Patrick: That’s great for them, man. He deserves that.

Daniel: Yeah, but man, I don’t know. Was it worth it? People always say how lucky or deserving he is, but I don’t think I’d make that sacrifice, and live like that, to have a million-dollar house.

Patrick: Yeah, I get you on that. He definitely fought for our freedom though.

Daniel: For sure. For our right to be free.

In this brief exchange (at KP), Daniel and Patrick both agree that Randy fought for “our right to be free.” In the calculus about how much assistance and how “deserving” Randy is of

such acts – in this case, the Gary Sinese Foundation building him a million-dollar home – two tensions emerge: (1) that Randy fought and was injured for a grander purpose, and (2) that this exchange is still not worth the cost (i.e., that not even a million-dollar home is worth a life with paralysis as severe as Randy’s). In a conversation about SCI, KP’s staff, who are fully abled, revert to deeming SCI as a transcendent position. A worst-case scenario.

As discussed above, Jack explains Randy’s purpose was to found KP, in order for all to coalesce there – even myself, as a researcher. On the other hand, Daniel and Patrick situate this purpose in the context of his service. In either case, the desire to situate Randy’s injury and debilitation in something tangible, specific, and grandiose (in magnitude) is used to add meaning to it. Sarah Phillips (2011, 2) describes pwSCI as feeling in a state of perpetual liminality due to having been given a purported “license to do nothing.” This ethical stance serves as the cultural expectation of the kind of pwSCI one ought to be, and so any transcendence of these expectations is situated as laudable and deserving of praise.

In the last two sections, I’ve illustrated how “acceptance” is deemed important at KP. Those whose personalities are easy-going and accepting are seen to be more capable of progress and an overall more positive life. Furthermore, many at KP define themselves as active and productive, with the ABT at KP aligning with their affective inclinations. In other words, those inclined towards intense exercises (hence, their conceptualization of KP as “the gym”) will find their home at KP. I argue that KP’s culture caters to certain individuals who are highly motivated – in addition to those who can pay for it (as discussed in Chapter 5). KP’s staff and rehab participants have somewhat aligning moralities. However, aside from the moral expectations of pwSCI, there exists another phenomenon surrounding “joking” that must be placed in context.

Examples of how this social dislocation is enacted at KP involves instances where individuals perform what I refer to as *joking as affect*.

Joking as Affect: Revitalizing and Re/acting to Debilitation

I believe the difference in the source of my struggle throughout this research (i.e., discovering “the true difference between physician recommendations and those of KP staff”) is that physicians stand further apart from patients while KP staff members have developed deep relationships with them – after all, they conduct 2-hour therapy sessions as much as 5 times per week. At KP, there is an exchange of *emotional energy* – which Randall Collins (2004, xii) describes as the product of collaborative “social rituals” which can either increase or decrease one’s emotional energy. As such, this section will point out instances of social dynamics that either drew out, or failed to draw out, copious amounts of emotional energy. I start with a brief interaction with Katie, KP’s Operations Manager.

I enter KP at 8am on Thursday, October 7. Upon walking in, I greet Jerome and his training aide Patrick, who are already working with a client: Beatriz. We exchange a brief “hi” as I walk to Katie’s office to place my bag down.

Will: Hey Katie, how are you doing?

Katie: Hey Will. I’m pretty good.

Will: I noticed someone new working here.

Katie: That’s a new intern that’ll be shadowing and helping around here for the next 5 weeks.

Will: A lot of students come through here, right?

Katie: Yeah, people here are really used to it. Interns and students coming through here. Like we had an OT student come through here last year. She recorded patient testimonials for her project. They're so used to telling their story.

***Staff laughing in the room next door.*

Katie: Have to get tested.

Will: Hm? For COVID?

Katie: I have to get them tested, mentally. They're acting wild this morning.

This brief excerpt was one of many instances where individuals joked about neurological disorders. In these instances, patients/clients were often spectators or simply on the receiving end of jokes made by staff members at KP, who engaged in lighthearted reorientations of the kinds of disabilities common for KP's participants. These events range from opportunistic moments to full-on joking about a given condition. In this section, I argue that such instances of joking are attempts to increase emotional energy in order to create a cohesive community at KP where all can develop a familiarity and camaraderie with one another.

A month earlier, on my first day at KP, Katie walks over to me, as I chat with Jack and Jessica, reminding me of a previous instruction to "stay away" from them both. Jessica jokes back with Katie, with Katie responding: "We're assuming she has an undiagnosed brain injury. It prevents impulse control." In instances like this, where I personally feel uncomfortable, but others do not, it became clear immediately that I had yet to become integrated into the affective relations between all at KP. In this space, a joke is only offensive if someone takes offense.

However, I was struck by how many clients/patients at KP, including Jessica herself, actually do have some level of TBI, as TBI is often comorbid with SCI, as many times, injuries affect many parts of the body. Diana made a similar joke about TBI, but this time to another staff

member. Diana was in the middle of explaining to me the clients and patients who were being cared for at KP at that moment, explaining that “Mr. Henry has neuropathy, spinal stenosis. He’s got MS (pointing to another patient). Randy has SCI, **Mark (trainer) says something while passing by Diana** and he’s (pointing at Mark) got a brain thing,” each of them laughing.

Such interactions are not coincidental or created by chance. In my interviews with KP’s staff, each explained to me the importance of “keeping conversations going,” lest they, “get to be pretty boring,” as indicated by Daniel:

Honestly, the most important thing is being able to build communication. You learn a lot of the hard skills, so to speak, in schooling. But it's hard for someone to teach you how to speak to someone if you've been shy all your life and you don't know how to carry a conversation. That's what's going to be the hardest thing here, especially in this setting. It's a two-hour session, if you can't keep some sort of conversation, or keep them motivated for two hours, it's gonna- you're gonna be hard pressed to have a good time yourself much less try to motivate your client.

This is best exemplified by Armando, a trainer who has been at KP since it opened, and who is also Randy’s nephew. He explains:

This experience. Working here was very eye-opening for me in the sense of, I used to think I was an introverted person because I’ve always- as an individual, always been quiet, to myself, you know, alone, maybe even sometimes. Just cause that’s the type of person I am. But this job forces you to step out of that zone. Forces you to- to lead. Forces you to become more outspoken. Outgoing. Uh. Forces you to think on the spot and be quick. So that’s what I have learned from being here. It definitely like- if you would have met me 6 years ago, I was completely different to the way I am now. Two completely different people.

Engaging with patients and clients requires KP staff to perform a bit of mental and emotional labor. They are attempting to hack the emotional energy circulating within an interaction in order to propel people’s bodies to perform well during rehabilitation sessions.

Most other instances of joking were done less at anyone’s expense – or, less directed at specific people per se. For instance, while Jack was working with an older patient, he coaches

this patient, Mr. Henry, on how he should orient his body while standing on a vibration plate. He instructs: “Mr. Henry, try to keep your knees flat. Don’t let them bend. Try to get your muscles to relax.” After a brief moment of silence, Jack continues: “I’m vibrating the piss out of you Henry. Squeeze your thigh muscles and pinch your butt. You don’t have to wiggle around though.” Jack and Mr. Henry laugh. In other instances, patients and clients at KP engage as well, such as a moment when Jessica’s therapist, Jack, walked away from her to grab an item to use for her next exercise. As she hung on the gait assist apparatus, Daniel asks Jessica, “Are you alright?” To which she responds, “Just hangin’ around,” which is met with laughter.

Most instances of joking were highly situational, such as this. As another example, in a moment where Beatriz (client) was seated alone, when both her trainer and the training aide walked away, Diana, who was working with a patient nearby, teased, “They left you alone like that? What a bunch of hoes.” I argue that such instances of situational/opportunistic joking are a part of the sociality at KP. On the one hand, it aligns with the cultural and ethical norms described above. On the other hand, I believe this form of joking is also related to the phenomenon of hope at KP. In order to illustrate this, I find it instructive to denote an ethnographic moment when repeated engagements to increase emotional energy are not reciprocated with a client/patient.

Motivation and Hope as a Biocultural Process Towards Healing

It is an early October morning and I have been coming to KP for about 3 weeks now. I come in at 8:21am, early enough that everyone is nearly finished with the stretching portion of rehabilitation sessions, which lasts anywhere from 15-20 minutes. I walk over to the bench where Daniel is preparing for a new exercise with a client named Robert. I introduce myself to

Robert, who nods. I ask if it would be alright with Robert if I stay and watch for a bit. He nods again.

I ask Daniel what the plan is for Robert's rehabilitation today. He replies, "we're going to be doing single laps around the room. We're doing these instead of the big ones," he finishes saying as he looks back at Robert. Before Daniel begins, he finishes off stretching Robert's right leg, with both looking away from one another. Robert is lying on an incline on the bench, which is set up with two soft wedge-shaped pads with a flat bosu ball placed under them, with Robert resting his back directly on the wedges.

Daniel tells Robert, "So I finished Alice in Borderland. It was alright." He continues, "It has a lot of parallels with Alice in Wonderland." Robert nods. Daniel indicates to me: "You can look at his chart." I notice during the stretching that Robert has two overlapping "Omega" signs branded on his right arm, indicating that he was in a fraternity. Daniel then begins to talk about Dave Chappelle's latest comedy special The Closer, saying "this one is definitely not as funny. That last one was just joke after joke after joke." We chat briefly about how this new special was controversial for its focus on transgender issues, but we don't go in very much depth. (Later that day, Jack would come in, applauding the new special, stating that Chappelle "goes hard on trannies, bro," turning to me, continuing, "I'm sorry, you're not- good with the pronouns? My pronoun game is eh.").

Daniel begins placing a blue belt around Robert's chest, saying that they will begin doing single laps. Robert walks with Daniel standing close enough to have one hand on the back of the belt tied around Robert's waist. Daniel gives Robert a goal of completing "10 laps with no breaks." The entire session continues in relative silence, with Daniel looking at other trainer-client pairs, like Beatriz, who is performing leg exercises on a nearby machine. Daniel notices

Robert is sweating, and so he asks, “Do you want the fan?” Without waiting for a response, he brings the fan over and points it directly at Robert.

After completing these laps, Robert takes a break, which continues in silence, with Daniel making comments about topics like the weather, traffic, and the upcoming holidays. Robert says a couple of words, but with the fan on, I cannot hear him. Daniel tells Robert that he will now be doing “reach-and-grabs,” where he will reach for small cones in order to have Robert stretch his body out “past what is comfortable.” Daniel explains that this will help with Robert’s balance and core strength. Halfway through the exercise, Robert mentions that he is feeling tired, with his back tightening up, but he completes the exercise unassisted.

During these exercises, Daniel strikes up a conversation with Tom, who is working with Carmen on a nearby bench. Daniel then uses this time to explain to me the situations and conditions of some of the patients and clients currently there at KP. He elaborates the extent of Tom’s injury, how long he has been here, and does the same with Beatriz and even Robert, who is just outside of ear shot from us. As I ask additional questions, the conversation continues, going on to talk about 5 other patients/clients I have met.

In these series of interactions, Robert does not reciprocate the interactions that Daniel repeatedly attempted to engage. As Daniel would later tell me, “Having Robert or Lucas can be pretty boring,” as Robert is relatively quiet, and Lucas has severe TBI that renders him nonverbal. Daniel would later explain:

You got to be able to- you're going to spend two hours of your own time with someone there too, and they might not be eliciting conversation, and that's going to be de-motivating for you too. Just being able to build that rapport with them you know... it's just- it's just better for you too because the two hours will go by so much easier if you're able to, you know, keep yourself motivated, because it is a little bit de-motivating... [it] changes your mental approach on how you're going to do things, and it's going to change how they're going to feel about your session too.

What Daniel explains here are instances where staff members attempt to incite emotional energy to propel motivation in clients/patients.

The interaction between staff and patients/clients is crucial to understanding the relationality at KP, which relies on building interpersonal connections – or empathetic interactions where empathy “arises only in the context of relations between fellow embodied expressive beings” (Throop and Zahavi 2020, 291). Per Daniel, the quality of such embodied interactions tends to determine patient motivations and determination and thus, potentially, their outcomes. Above, Robert was not engaged with Daniel, and after some attempts to incite conversations, Daniel resigned himself to engage with me and/or other therapeutic pairs on the KP rehabilitation floor. The quality of such interactions was seen to be important to the quality of the therapy itself.

For instance, Jack explains that he also attempts to get to know patients in order to situate their rehabilitation sessions. He explains, “that's why I like- I talk to them. And I ask questions like, ‘what did you like to do?’ ‘What are you into?’ What- you know, ‘I like fishing.’ Okay well, ‘okay, let's work on your posture,’ ‘let's work on your grip,’ ‘let's work on this,’ let's see where we're at...” Jack elaborates further, explaining that his strategy is to have conversations with patients in order to help him construct their goals. Indeed, after finding out about Jessica’s interests in one day resuming her jiu jitsu lessons, Jack explains that “helping her with her transfers will also help her move on a mat.” This project of translating movements across contexts is hugely important to the kind of physical therapy performed at KP.

However, joking, especially for Jack, is a means of staying mutually engaged with a patient. Rather than his comment on “trannies” being meant to offend or provoke anyone, in context, this comment was said at KP – a setting where all are expected to be able to roll with the

punches.⁷ Indeed, the cultural environment at KP encourages individuals to be "tough," be able to "joke," and to be emotionally resilient (which we might say coincides with the physical resilience patients and clients are expected to develop). For instance, in a session where Jack is engaged with Jessica, who is standing on a vibration plate with her body being supported by a sling, Jack tells her, once he has her situated, that, "You're great, you're all stacked up," while both he and Jessica look in the large mirror in front of her, analyzing her posture. As she squats down, with assistance from Jack and another training aide, Jack instructs Jessica: "Squeeze your butt like you're pinching a quarter. An old stripper trick." These jokes incite strong laughter and a bit of shock. In retrospect, the shock and discomfort I felt at the start of my time at KP was likely *the point*. After all, strong emotions have a greater chance of inciting more emotional energy than weaker ones. And what incites stronger emotions than provocative comments?

In many cases, this banter went back-and-forth between patients and KP staff, such as the following instance involving Ray (patient), Jack, and Daniel, where Jack initiates an interaction, making fun of Daniel, whose 'buttock' was showing, drawing Ray into the interaction:

Jack: Your crack is showing. Ray doesn't like it.

Daniel: Why are you looking?

Ray: I get blamed for everything.

Daniel: Jack is only saying something because Ray is here.

Ray: I'm from the 80's, I know crack kills.

(Daniel and Jack shoot each other a wink and a nod.)

Prior to this interaction, Jack and Ray were coming across some issues in their rehabilitation session where Ray was unable to keep standing on the stand-assist apparatus. His

⁷ And, because there are no trans-identifying individuals either on staff or as a patient/client, a space like KP likely does not need to consider those particular dimensions of inclusion.

spirits were a bit deflated in a moment where Jack initiated a humorous moment at Daniel's expense. Relevantly, Jack, Daniel, and many of the male staff members at KP are all involved in a fantasy football league. Indeed, popular media was also used to draw people into conversation, as exemplified by Daniel's attempt to initiate conversation with Robert above, as well as Daniel's and Jack's statements about the Dave Chappelle special.

Given the failure to incite engagement with Robert, and how KP's ethical stances are so consonant with individuals' preferences and identities, it seems that ABT as a set of procedures must be distinguished from ABT as an ethos. Emotional energy is incited in ways that are culturally relevant and intelligible to KP's rehab participants. In addition, focusing on methods for inciting interesting conversations is crucial to the philosophy of therapy provided at KP – i.e., where culturally relevant incitements of emotional energy are used to propel effective ABT. As indicated by KP staff and participants, long-term rehabilitation can be mundane and repetitive.

Bare Repetitions at KP

I would like to contextualize the data presented above considering the Deleuzian theorization of difference and repetition introduced in Chapter 2. I have introduced data on the kinds of (hopeful) interactions that matter to rehabilitation. Joking is one such phenomenon that re-emerges at KP, and it fits perfectly within the dominant relational ethic at KP that promotes both lightheartedness and toughness. In addition, I have discussed how KP's rehabilitation participants communicate instances of being truly affected by others, which helps shake them out of whatever complacencies that plagued them – in James' case, accepting that he doesn't have it “hard” like the boy he identified. All these data signal ways that pwSCI at KP can make room for uncertainty in a way that is productive. Thus, KP staff wish for pwSCI to “accept” their situation not to relegate them to hopelessness, but to make room for possibility and thus, more productive

therapy sessions. To properly contextualize all these themes, I'd like to return to the core theoretical concepts of this dissertation.

As discussed in depth in Chapter 2, Deleuze argues that difference is often predicated on identity – a dogmatic “image of truth” that ends up shaping all our attempts to *think* in the world (i.e., when we compare, contrast, or think about what makes difference). Repetition is a related concept because the narrative that difference between two objects denotes a difference in their core identity tends to influence how we conceive of repetition as a “bare” repetition of the same phenomenon. In other words, we reinforce a dogma about Sameness, that obscures the fact that the world is filled with relational processes that determine that all repetitions be condemned to inherent difference. Thus, difference exists through repetition.

Deleuze (1994, 18) inverts Freud, arguing that “we do not repeat because we repress, we repress because we repeat.” Repetition is not the result of a forgetting, but instead creates/reinforces forgetting. This means that the very idea of a “bare” (i.e., true or pure) repetition is a mental construction that leads to a series of consequential assumptions. Hence, the presence of a dogmatic image of thought that forces thinking in what Deleuze considers to be unhelpful (even erroneous) directions because we repress parts of our affects and our experiences in order to create an image of reality that is relationally intelligible. Enculturated beings seek to create dogmas, not value-free truths.

This construction occurs through regimes of truth – the naturalized dogmas that are tacit, yet immanent to human rationalizations. Hence, the secondary level rationalizations that perpetuate the kinds of expressions that come easily to pwSCI at KP. We internalize cultural ethics that lead us to reinforce these dogmas. In this sense, the unconscious is less a stable

structure and more of a culturally constructed one. We repress that which does not allow us to experience it (an event, an identity, or even an emotion) as a “bare” repetition.

However, we also gain an understanding about life by situating aspects of it along a meaningful continuity – such as where the rehabilitation process becomes akin to human development from infancy to adulthood (such is the logic of ABT’s Dardzinsky Method). Thus, such images of thought are not merely illusory, but create reality. Ontological. Such fictions are not only useful, but fundamental to human experience. In this research, the development narrative (i.e., that injury rolls one’s body back to a previous stage of life; a bare repetition of it) enables KP staff to create a plan of care for patients and clients.

As Jared explains,

Nobody wants to restart from the- from the start, you know, so we have to go back to the primitive like the crawling stuff, nobody wants to start crawling, you know. But um. It's- which is what's going to help them progress as much right. So- they want- it's not a bad thing to obviously want to do more than what you can but. Just knowing when to take a step back and realize that “Okay, maybe I should work on being able to hold myself up and sitting first, before I want to start walking,” right. You have to build the foundation first and then. Then they go up from there.

Rebuilding this foundation is conceptually linear and rational. Crawling comes before standing, which comes before walking. Building these capabilities back up means re-engaging with “primitive” processes such as these. “Foundational” applies both to the logic of therapy as well as to how the logic of human development is seen to function. This concept of repetition interplays with a different kind of repetition: that of how therapy and the body (re: functional mobility) work.

In a conversation with Randy, he explained that his impetus for founding KP rested in the therapy he received from the local VA, which he defines as “more conservative.” “Sitting is detrimental for the body, and the VA is less willing to do things like weight-bearing, which is

great for stuff like bone density.” For Randy, the body’s very adaptation – and thus, the repetitive action of sitting itself – can be detrimental over time. This resonates with Robert Murphy’s (1990, 166) description of his body’s deterioration into increasingly debilitating SCI, explaining, “There is a relationship of positive feedback between usage and capacity; that is, they amplify each other. The more one uses one’s legs, the greater will be their capability; similarly, disuse leads rapidly to atrophy and loss of potential for function.” Hence, repetition can be useful or harmful as what exists gets amplified.

This logic helps justify KP’s imperative of getting people out of their chairs. This new kind of repetition helps deliver greater benefits to KP’s clients and patients. Furthermore, this repetition helps promote rehabilitation where, “Following loss of function and mobility through injury or disease, a person needs to establish a new sense of embodiment, cognitively, neurologically and physically reorganizing the body schema, re-learning tasks that were near automatic” (Manderson 2011, 96). Such repetitions are crucial to developing a new sense of normal. Despite these benefits, and the fact that these exercises help maintain patients’ and clients’ overall health – preventing deterioration – KP staff often alluded to therapy being a bare repetition, comparing it to the film, *Groundhog Day*. For instance, Daniel explains:

It's just so routine here, it almost turns into *Groundhog Day*, which is why we try to be as creative as possible right because if someone's say- one of the patients has been here for four years, and I've been working with them for four years, I've been doing the exact same thing then, right. We all have been especially for the guys that have been here long. Me, Armando for sure, and then Jack like. We- we're better when we have like, new people, because then we can just go back into our repertoire and pull from that and now, we're like kind of like renewed. Now we can see the processes all over again versus when you're working with the same person for four years.

At some point, for Daniel, he describes getting lost in the image of the repetition, and only interacting with a new client can incite some creativity for him, as a trainer guiding clients through their sessions. It is not necessarily that repetition is wrong, but the kind of healing for

long-term rehabilitation clients such as pwSCI means that progress and recovery is a slow-going process, creating the illusion of bare repetition.

Jack describes the same experience, using similar comparisons:

Okay, and I don't mean to sound like a dick when I say this but, you know for me personally I've been here going on fi- I've been here for five years. And I have patients that I've been treating for five years, you know. And so, sometimes it can seem like *Groundhog Day*, like you're just doing the same thing over and over and over and over. But then the day comes, where they make a really- they're able to do something that they were never able to do before, or they- they get- They make some kind of, progressively, that they hadn't done and then it makes it all worth it, you know. So, you know- it's- you know- you're- you're- it's a two-hour session so we're- we're doing stretching, which is very important too, and I think that the stretching. I always try to reiterate with, especially we got a lot of new people out there, the stretching is really important. You know, and I think a lot of that gets overlooked, because it kind of just becomes rote.

Jack describes how the repetition of therapy can lead trainers and physical therapists to neglect the importance of each aspect to therapeutic healing and recovery. Indeed, reflecting back on someone like Tom, whose contractures in his left arm are in need of relaxation and flexibility, stretching alone can have significant impacts on well-being and quality of life. This is his doctor's justification for seeking massage and stretching rather than ABT.

For both Daniel and Jack, repetitions are a part of KP's rehabilitation. Very rarely have they seen patients and clients begin walking again – though it has happened. This therapy modality is geared towards patients who have biomedically defined “stable,” chronic conditions. Clients such as Sam describe how this plays out at other facilities, where repetition can often lead to ceasing rehabilitation sessions:

[Hospital] is not a spinal cord injury focused rehab facility. There- there are a lot of different injury types, so they- they did not have the spinal cord injury focus that KP has. However, they did do a good amount of stuff that helped me along and I think we just reached a peak as far as that, they really couldn't do- do much more other than just continuing to repeat the same things which weren't really getting me much gains. Plus, the sessions were only 45 minutes long, which was not enough time to be able to, you

know, make significant gains. So, the approach that [Hospital] takes is very different, and that's obviously for a reason: they're not a spinal cord injury rehab facility.

This adds context to what Caitlyn describes near the start of Chapter 4, where the local hospital told her she “was too good to have goals.” Rather than this being situated within some objective evaluation about her body, we see that the logic of care immanent to a given facility makes a certain prognosis inevitable, given how measures are constructed.

In a 45-minute session, repetition denotes a lack of meaningful progress, leading facilities to prioritize those who would fit well into this therapy logic – i.e., those capable of significant, timely progress. KP’s rehab participants communicated this to me in terms of “hope” that physicians and traditional modality physical therapists tended to take away from them. However, the intentionality implied by such descriptions merely relate the effect of such definitions: that this bureaucratic, “audit culture” oriented designation has very real consequences. Individuals are only feeling abandoned, but in effect, they are left with little recourse to pursue rehabilitation – especially if they do not yet qualify for Medicare insurance.

Thus, temporality is important here as it creates the conditions both necessary for, and consistent with, care logics. More rapid, 45-minute sessions do not work well with the kind of donor-supported, and morally laden, care put forth by ABT at KP. One where several ethical imperatives exist, such as taking people out of chairs, and getting patients and clients as active as possible according to their ability. However, in their interactions, KP staff and rehab participants draw on the culture they co-construct there in order to incite motivation during rehabilitation sessions.

Discussion

In this chapter, I've discussed the transcendental ideals at KP, where pwSCI see their debilitation as a worst-case scenario, and where KP staff reinforce this reaction by doing the same. PwSCI at KP thus inhabit this extra/ordinary position where they navigate their injuries as a normal part of daily living, while also being a model for a worst-case scenario. To support effective therapy outcomes, rehab participants must learn to accept their situation. Only acceptance will enable effective therapies. Thus, long-term clients like Kevin tend to accept that they may never walk again. However, this does not produce the kind of listlessness that physician recommendations do because the robust cultural dynamics at KP still reinforce the ideal of driving forward and advancing – as illustrated by the philosophy of the Dardzinski Method.

One's ability to perform this optimism is said to inhere in who a person is. Indeed, the ability to laugh at jokes, even when one is the butt of it, is a part of the expectation of who one ought to be at KP, and these dynamics are largely dictated by KP staff. However, ethnographic scenarios seem to indicate that not all can fit into this ethic, calling into question the utility of therapy like ABT at KP. How inclusive can this therapy modality be? Is it possible for someone not interested in exercise and sports to find a place at KP? Given the failure of the social ritual (and incitement of emotional energy) between Robert and Daniel, what might be the long-term consequences of such disengagements for other rehab participants?

Lastly, this chapter also helps clarify certain statements, such as being “too good to have goals” as well as that “Medicine has shown that doing these exercises daily doesn't have a huge benefit” as it is a “divergent mode of care.” Instead of being objective statements, we see that they merely occupy a different logic/regime of care, which organizes/structures truth quite

differently. These statements are linked with moral prescriptions – that one should spend their time doing something more productive. They are also consonant with institutional prerogatives – they are true within the systems in which they are stated, but not necessarily for patients, or for a long-term care modality like non-profit ABT therapy, especially one like KP that has a donor-supported structure that curbs costs for clients. The next chapter serves as a discussion of all of the themes from this dissertation, illustrating the three-level approach by centering the phenomenon of hope.

Chapter Seven: Discussions

Hope doesn't have a conclusion to it. It doesn't have a final opening into the light. But it does offer the chance of new beginnings... life is always exceeding itself, overtaking itself... Life is always opening to pure possibility, and that's what allows it to carry on, and that is what opens up an avenue for hope which is not about reaching the final answer, but it is about there being life for the generations that will come after us.

- Tim Ingold (2022)

This dissertation has engaged with hope – such as the hope that some of my pwSCI interlocutors may walk again. However, as the above excerpt by Ingold suggests, true hope may instead be situated in ambiguous futures rather than optimistic ones. For many, physicians seem to discount a possibility of this “hope” by bluntly explaining to their patients that rehabilitation is unlikely to help them regain functional mobility and may in fact present undue risks. Does such a prescription posit pessimism, or a more open-ended approach to the future? The answer to this question depends on the interlocution process and its participants.

Theorizing hope has often depended on situating hope as an optimistic endeavor. This reveals a need to explore the ontology of hope that anthropologists often construct in their analyses. Nevertheless, such literature also offers guidance on how interlocutors often engage with their own insights about the future. Per Vincent Crapanzano (2003, 24-25), hope is defined in terms of desire, such as of an object one covets, or an outcome one wishes or dreams for. This is akin to what William Lempert (2018, 203) refers to as “generative hope,” where our analysis

of, for instance, the confrontation between “indigenous futurisms” and “colonial damage” can reveal routes of alternative, optimistic futures. In each of these, hope is equated with optimisms and “projected into the future” (Lempert 2018, 204) where, “hope” is a contested outcome.

Hirokazu Miyazaki (2006, 163) describes conflicting optimisms – where one man’s “hope” for the future (such as his friend Tada’s hope for a business venture that he hopes would deconstruct capitalism) conflicts with his own (where Miyazaki maintained doubts, hesitations, and outright disagreements with this aim), as Miyazaki did not share these similar “hopes.” Such theorization of hope situates it as a “critique” in the sense that one’s optimistic vision of the future serves as a legitimate focus revealing gaps in one’s current position and situation (Miyazaki 2006, 164). In these conceptualizations, hope is undoubtedly linked to optimistic projections of the future. However, such reflections also result from precisely where one exists. Such as in dire circumstances or in such a subject position where one is capable of critiquing one’s circumstances. Thus, hope reveals one’s own situational competence.

Such considerations are pushed even further with theorizing on the intersections of hope and politics – where one’s legitimacy to speak on one’s own behalf is placed within intersubjective political contexts. For example, Lesley Gill (2006, 9-10) situates hope as linked with political alternatives where unionization efforts in Colombia (regarding workers’ rights vis-à-vis a local Coca-Cola plant) are stamped out by assassinations and intimidation efforts that served to diminish political alternatives. Thus, “hope” is linked to *overt* attempts to politically diminish people’s collective and individual capabilities.

At a more *symbolic* level, Mattingly (2010) describes hope in her study on African American caregivers of children with chronic health issues. There she defines hope as a dichotomy between optimistic and pessimistic outcomes – with clinicians being unaware of the

stigmatizing effect of a “noncompliance” label (ibid., 86), and families’ struggles for the American Dream in an “against all odds” fashion maintaining the optimistic hopeful stance others describe (ibid., 15). Such a framing of hope is crucial for Mattingly as it centers how intersectionally contingent “hope” can be. Some are afforded more leeway in their hope – where their positionality facilitates more or less of it, and in which not all Americans are made to reside.

Lastly, Eleonor Antelius (2007, 324) positions hope as a temporal concept where “action taken in the present could bring about (positive) change in the future.” While hope is similarly connected to positive, optimistic outcomes, Antelius complicates it by linking it to “narrative foreclosure,” where individuals’ dire circumstances often stamp out hope altogether (ibid.). This is especially relevant for this dissertation, where I have previously suggested that pwSCI necessarily engage with other pwSCI whose novel, impactful, and noteworthy situations affect them in unexpected and significant ways. This is also linked closely with Ingold’s notion of hope in that, moving beyond the optimistic narrative of hope, Antelius brilliantly defines hope as needing to be “understood in relation to the personnel’s dilemma of joining a sense of narrative foreclosure with their job of motivating the participants to physical action” (ibid.). Hope is thus what propels action and is not necessarily about specific optimistic outcomes that participants can identify and believe (i.e., desire) for themselves.

This chapter uses the phenomenon of *hope* as a means of discussing the main themes presented throughout this dissertation, especially as they pertain to the three-level model presented in Chapter 2. However, it will also theorize hope phenomenologically. Put another way, this chapter discusses data presented in Chapters 4 through 6, situating these within the three-level theoretical model presented in Chapter 2. I do this by centering *hope*, showing that

hope is not merely linked to optimistic outcomes, but is also situational and subjective (i.e., cultural) as well as useful in rehabilitation practice (i.e., physiological). This helps define hope as inherently biocultural due to how (1) different physiological capabilities are naturalized as having a certain propensity for hope, thus tying hope to the body, its capabilities, and future prognoses; (2) hope is engaged with cultural processes that code bodies differentially; and (3) these cultural paradigms can often serve to constrain notions of hope (i.e., as optimistic or pessimistic), but over time, the process of rehabilitation can instill a new ontology of hope that engages with people's own inherent interests to engage. I refer to this latter facet as object-oriented and process-oriented ontologies of hope. I consider this biocultural as cultural paradigms may serve to delimit what is possible, despite the body's actual processes, which reveal an inherent propensity for recovery no matter how modest it may be. The three-level approach used throughout this dissertation can aid with seeing how biocultural hope functions.

The Three Level Approach, Redux

This chapter illustrates the concrete ways that affects, policy/political economy, and moral rationales can all co-exist side-by-side in ethnography. First, I present a brief overview of the data presented so far. In the previous chapter, Chapter 6, I defined “ethical affects” as unconscious and naturalized feelings that are both culturally molded and exist temporally in ethnographic text. I have heretofore argued that this unconscious level tends to have undue influence over human daily life due to its tacit nature – which is created through how it inhabits a more ambiguous space compared to more explicit moral rationales, which themselves constitute and enforce a more certain, dogmatic regime of truth.

Such dogmas were exemplified in the chapter before, Chapter 5, using both structuralism as well as Graeber's “creative refusal,” where cultural identities are often predicated upon whom

one is *not* (Graeber 2013b, 1). Such refusals (as well as the assertions they imply) are exemplified in how ABT at KP is often situated contra “traditional therapy,” which KP therapists and patients define as less hopeful due to fewer opportunities available for bodily healing. This is also exemplified in the chapter before that, Chapter 4, where I use various pwSCI case studies to articulate the specifically stated moral grounds upon which individuals construct their own subjectivities – such as how Tom’s status as a veteran proffers a specific kind of continued duty while his status as an SCI patient shapes the relatively passive nature of such duties. In such case studies, pwSCI are evaluated and funneled towards increasingly restrictive activities through both intersubjective narratives and the normative structure of SCI. While not a product of explicit discriminatory sentiments, the outcome still reproduces exclusion.

Chapter 6 focused on the primary level of unconscious ethical affects, which may imply that this “primary” level is somehow privileged or may occur first. However, this is not the case as not all human subjectivity stems linearly from this tacit ambiguity. This flow is important because I believe anthropologists risk cutting off our ethnographic analyses by ignoring what I believe to be a fundamentally ethical context. For instance: the three-level model introduced in Chapter 2 (Figure 1).

This framework is circular because as “logical structures” are more amenable to definition and conceptualization (along with being more enforceable and articulable in human social life), our mental and social categories (i.e., regimes of truth) become influenced, creating new normative/normal subjectivities (primary ethical affects). However, as Ingold (2022) argues, “There’s more to [living in the world]... There is an impulse to life beyond a merely objective relation to things.” Thus, we never reach a stasis or stability. He thus contrasts optimism to hope, where optimism is tied to a specific conclusion or outcome, but “hope doesn’t have a conclusion

to it. It doesn't have a final opening into the light. But it does offer the chance of new beginnings" (Ingold 2022). Wildly ambiguous, however, I argue that as we explore such ambiguities, we tend towards new or modified dogmas rather than a lack of dogma altogether.

This line of thinking is crucial as it illuminates the mechanism through which interlocutor discrepancies (i.e., the contradictions between what people say and do) exist. Not only through repetition, where relations intensify and create radical forms, but also through an inherent lack of (and impossibility of) faithful recognition. Hence, the distinction between morality and ethics. Traditionally in philosophy, ethics is linked with cultural norms rather than value judgments – they are the flavor that a given life acquires vis-à-vis the ways in which it is lived according to a given ethos (Fassin 2009). This is separable from culturally enforced (moral) values/judgments, which are often forced into alignment with other cultural rationalities. However, ethics is much less determinate.

In anthropology, it is often narrative ethnography that is linked with such indeterminacy, such as the Brunerian subjunctive mode, which stems from Jerome Bruner's exploration of possibilities over whatever certainties we believe to exist (Bruner 1986). This is where life occurs "in the middle" (Mattingly 2010, 53), and where "narrative succeeds by 'subjunctivizing' reality... by exploring the indeterminacy of reality and stimulating such exploration in the reader" (Good 1994, 153). However, I have argued that affect occurs at this level as well, as affects communicate the "erratic" nature of this indeterminate reality (Stewart 2007, 3). As ethics is defined as one's inclinations toward a certain kind of life, I define affect as how this kind of life is lived and experienced. In sum, affects are how ethics become expressed in the everyday.

Illustrating the links between affects and ethics (as a primary level phenomenon) also requires engaging with secondary (moral) and tertiary (dogmatic/mental categorical) levels. For instance, Veena Das (2012, 134) has argued:

for a shift in perspective from thinking of ethics as made up of judgments we arrive at when we stand away from our ordinary practices to that of thinking of the ethical as a dimension of everyday life in which we are not aspiring to escape the ordinary but rather to descend into it as a way of becoming moral subjects ... through the cultivation of sensibilities within the everyday.

Das (2020, 15) often centers themes of violence, hardships, threats, and loss in her work. Her work describes moments when we are moved; when the reactive forces of our lives impinge on us and when we are moved to re/act in one way or another. After all, a life is also always in the process of being lived. We can never wholly disconnect the social/moral from the ethical affective.

Anthropologists have variously engaged with affects, situating them as linked to cultural knowledge while illuminating dynamics often hidden from ethnographers. For instance, Dominik Mattes (in Stodulka, Selim, Mattes 2018) describes a clinical scene where the death of a child from HIV – where they are described as frail, sobbing, and with yellow and “waxen lips” – is placed into context with another scene where the mouth of a child with HIV is wrenched open in order to ensure her adequate nutrition, which Mattes had initially interpreted as “the result of the matron’s pedagogical irresponsibility and lacking empathy” (Stodulka et al. 2018, 529).

However, a focus on affects helps complicate such a linear interpretation, in which Mattes comes to interpret this scene in the light of the suffering of a child dying of HIV. As Mattes describes, such a scene often compels us to dichotomize two rationalities: what Mol (2008) would define as a logic of care (where the imperative to administer care is prioritized) versus a logic of choice

(where the imperative of patient choice, where the patient is seen as a rational, independent actor is prioritized).

However, as Mattes and Mol independently argue, such an ideological dichotomy obscures the care immanent in such scenes as force-feeding a child (where nurses effectively cut off her airways temporarily as they stuff food in her mouth) as well as how the choice a patient makes can and should determine the kind of care offered rather than foreclosing care altogether (such as choosing to sit with a depressed patient who refuses to eat, rather than leaving that patient alone merely because it was their “choice”; Mol 2008, xi). Thus, this regime of truth (where we can administer care *or* choice, but not both) engages life on a moral level (of right versus wrong; good versus bad; choice versus care) but fails to account for the ambiguity inherent in such human interactions (i.e., the experience of all involved as thinking and feeling subjects and how they navigate the options available). *Though moral categories exist on a secondary level rational system, the ambiguity inherent within primary ethical affects reveals instances when neat categories fail.* And it seems that inevitably, they do fail.

As an example, Jiyoung Yun (2021) situates affects within “affective communities,” describing scenes of role-playing in which the kinds of fictive familial relationships that individuals craft can often cater to neoliberal standards. In Yun’s research, this involves increasing student success while also helping to shape the neoliberal economy that structured it – such as where Gijeong, a “chief project manager” outlined his role in both parental and bureaucratic terms where students learn valuable tangible skills in a familial social context (such as where Gijeong plays a fatherly role; Yun 2021, 79-80). This work situates affects as culturally and economically engaged and motivated. Affects are sensitive to tacit standards of success and can be leveraged to help all members of a community, violating the individualism often argued

to be a main component of neoliberal sociality. Here, neoliberal ethical standards of rugged individualism are violated when placed in the context of everyday affective relationships.

Lastly, following Sasha Newell (2018), who links affect to the autonomic nervous system where recipients can recognize and reproduce affects and their meanings without necessarily understanding it, I see affects and their semiotic engagements as *entelechy* – the process by which the potential is made actual and where life is the product of sign processes (including their circulation, interpretation, and transmission). These sign processes occur via “affective transmissions” – communication that is both sensation and reaction not captured by ordinary language (Brennan 2004). Here, affects are both a product of these processes while exceeding their conceptual constraints.

Each of these engagements with affect theory: (1) explicitly situate affects within cultural, historical, and economic relations. They (2) reveal the limitations of typical and often unquestioned regimes of truth. Lastly, (3) they show that the ethical affects (primary level) captured in ethnographic moments (i.e., interpreted by anthropologists) are valuable for simultaneously situating/identifying cultural rules (tertiary level) and how they are socially and psychologically enforced (secondary level). Indeed, we often drawn boundaries between these when we conceptualize our ethnographic work (e.g., politics versus affects; or entire subgenres of anthropology such as “political economy” versus “psychological anthropology”).

Unlike Fassin (2009), who argues that moral evaluations and ethical norms are indistinguishable in ethnography, I retain this philosophical distinction as I argue that the temporality of ethical norms (their historicity as well as their often-implicit continuity in ethnography) differs from the near-fantastical life of socioculturally constructed categories and moral evaluations (which are hyper-rational and exist primarily out of a cultural consensus). For

instance, the regime of truth (tertiary level) that compels us to create and enforce dichotomous relations in our intersubjectivities with one another (secondary level), despite their inability to explain much in our ethnographic texts, stems from such moral evaluations, while our engagements with the human subjunctive occurs via eminent affects which are historical and ever changing (primary level). While conceptually separate, this three-level approach engages with their relation to one another, arguing that our moral prescriptions can hint at the ethical lives of our interlocutors. To illustrate this, in the next section I present a story by Armando, who describes an interaction with a client at KP.

The Phenomenon of Hope

Armando: Recently within, I want to say within the last two months, I actually had a- I don't want to say a fight, because it wasn't a fight, but it was a disagreement with one of my clients. Because now, this is a client that has like- I believe he mentioned he has ADHD and anxiety and suffers from depression and many other things. And one day we were doing an exercise and he kept asking me, "Did you feel something, did you feel something?" And I'm not going to lie to you. If I don't feel anything, if I don't feel the muscle activating, then I'm going to tell you the truth, and I'm going to say "No."

Will: Yeah.

Armando: He's like, he got pretty bummed out at the fact that he couldn't- that I couldn't feel anything on his legs. Then one day at another session. I was getting him ready, getting this equipment to one of the bikes, and he's talking to Jerome. How I put

him down and told him that he will never walk again, and then I was like- I was- I got pretty upset.

Will: Yeah.

Armando: Very upset because that was never what I said. I said, you know, "I don't feel any muscle activation on your legs when we're doing that specific exercise." Because this person, they are a Christian and they- you will see this person constantly praying during their sessions and like, I think it's very- it's nice that they have something to look forward to, that they have hope. I think it keeps people in a good mental state. But you got to also be realistic and I'm not going to lie to you or sugar coat it and tell you, "Maybe I feel something." No, if I don't feel anything I'm going to tell you that, and you know, maybe it's not the response you're expecting, but that's what I'm going to give you, that raw honesty, you know.

Will: Yeah

Armando: So anyways we had a disagreement, and I was very upset because I don't like being called a liar. I do not like that, especially in front of somebody else like now you are, you know telling this other person that I'm a liar because I told you, you will never walk again. It's like, how do you go from "I don't feel any muscle activation on your legs," to "you will never walk again"? Like to me he was just exaggerating. It got to the point where I just stopped- "You know what, let's not talk for the rest of the session. I just cannot- I'm having a physical reaction to what you're saying right now and then getting upset."

This story by Armando is important for a few themes that it brings into perspective. The first is the physician prognosis that patients will be unable to recover past certain bodily capabilities. However, as Armando argues, “It’s nice that they have something to look forward to, that they have hope. I think it keeps people in a good mental state. But you got to also be realistic...” KP staff are engaged in a sort of narrative re-envisioning themselves – which Mattingly (2013, 9) argues is “The re-imagining of oneself, one’s family, one’s life, is not a private introspective matter, some sort of internal story one tells oneself (though it may be all that too) so much as an active, creative remaking of daily life through the development of just such routines.” Through the rehabilitation process, where clients and patients get to physically practice their bodies’ limitations, I argue that pwSCI at KP are offered an opportunity to re-envision a new story for themselves. A new trajectory exists, emerges outside of the normative images of thought: i.e., hopefully and optimistically “walking again” versus hopelessly and pessimistically being disabled.

As Daniel mentions to me regarding another KP patients named Derrick, “If you’ll be here until March, then you’ll most likely meet him. He was supposed to be back last week, but he was admitted to the hospital.” Daniel mentions that Derrick has been to several ABT centers in Florida and has used their exoskeleton devices, and that Derrick (supported by his mother) still has a lot of hope, even though, as Daniel mentions, his x-rays “looked really bad.”

I then ask Daniel if there is anything that he’s noticed since working at KP, to which he responded, “Mostly the mindset of people.” Daniel explains that rehabilitation participants often transition from thinking that they may walk again, to accepting that they may never do so. Alternatively, people who have attended therapy for a shorter period of time have the attitude of what Daniel states as, “I will walk again.” So, clients and patients at KP have different

expectations about their recovery process based on the length of time at KP. Such sentiments are echoed by Armando and Jack, the two other staff members who have worked at KP the longest. Unprompted, Daniel clarifies that “We’re not taking [hope] away.”

My struggle to understand the difference between physician recommendations and those of KP staff in Chapter 6 reemerges here, and I believe the above vignette reveals the answer. At KP, staff have more sustained and consequential interactions with patients and clients – i.e., they are invested in them, and their remarks (and accusations) exist in a sociality with which physicians do not have to engage. KP staff’s very accessibility is what makes their interactions and claims (and appeals to be “realistic”) different from physicians. As stated throughout this dissertation, several staff members argue for some level of acceptance. Such as Jack, who applauded Kevin’s acceptance. This is also implied in Kevin’s statements about Caleb’s mother, Leslie, who he argues is holding her son back from accepting his situation by preventing him from obtaining an implanted catheter because – per his conversations with her – “she can’t accept that this might be forever.”

Indeed, in my conversations with Leslie, she argues that her means of “Ensuring he will be okay if I dropped dead today is to make him fight for his independence,” so that, “he doesn’t need me as much.” However, per Daniel’s observations, might this state of mind be temporary? After all, Caleb was injured for one year by the time of this conversation with Leslie. All at KP argue for some level of acceptance, but how this acceptance is defined varies greatly. What makes the difference?

The Social/Moral Rationale of Hope

Following Ingold (2022), I believe that “hope which is not about reaching the final answer, but it is about there being life for the generations that will come after us.” This is

exemplified by Antelius (2007, 338), who describes her clinical work at the Boost (a Swedish day center with TBI patients) where clinicians reignite hope in ways her interlocutors could never have previously anticipated. In other words, hope is not merely optimism, but it's the acceptance of uncertainty. Or a means of contradicting the "narrative foreclosure" people deem as immanent to their chronic conditions and injuries (Antelius 2007, 338). This is valuable given the certainty that SCI granted many of my interlocutors – the certainty that they "lost" their life, or that they are less capable, more dependent, and more abandoned.

To help theoretically contextualize this further, I'd like to link hope to another concept: nihilism. As Daniel W. Smith (2012, 177) argues, "nihilism, for Nietzsche, is nothing other than the triumph of transcendence, the point where life itself is given a value of nil, nihil." In transcendence – the affirming of *a* moral rightness – we reach a state where we are unable to act because we have already set out "the final answer" that Ingold defies. For example, when I first spoke with Jessica, she applauded KP for assisting her in increasing her functional mobility enough to be able to transfer herself to and from her wheelchair – capabilities that were foreclosed to her by her physician's prognoses.

In our first interview, Jessica contradicted pessimism with optimism – despair with a hopeful outcome. She explained, "My goal is to walk out the door, that's my main goal." This is often the hope that physicians attempt to contradict—the kind that they interpret as unrealistic and potentially dangerous. However, Jessica described how she "thrives" in proving her doctors wrong. Towards the end of my research, however, Jessica explained to me that, "I think I've accepted that I probably won't walk again. But I'm still going to go to therapy and grind as hard as I can, because I've made so much progress and I know my body can make more."

I believe the phenomenon Daniel, Jack, Carmen, and others at KP identify (where patients single-mindedly want to walk again) is a patient's initial inclination to meet what they see as pessimism, with optimism. However, as in Armando's story, sometimes what a patient identifies as pessimism or cruelty reflects how they might be dealing with a biosocial trauma – the confluence of physical and social dislocation. In an initial attempt to react to injury, SCI rehabilitation participants express a desire to regain bodily capabilities lost. However, over time, might patients accept the ambiguity of their situation, living in the progress made (and the progress to come) while “accepting” that an ultimate progress (i.e., a return to “normal”) might be out of reach? These two “acceptances” have the potential of canceling one another out. Unending progress enables one's regaining of significant physical functioning; and, accepting that one may not walk again may open the door to novel therapies at KP, which can also enable recovery progress. Thus, Ingold's “hope” might be seen in how therapy functions on and in the body.

Exploring the Structure (and Physiology) of Hope: Evaluating Hope as Biocultural

I previously mentioned Jared, one of KP's PTAs who told me how patients who get fixated on practicing their walking can present difficulties to their progress, as such a focus can detract from therapies, such as core exercises, that would bring about increased functional mobility. Thus, hope for walking again can detract from neuroplastic healing. With this new definition of hope, as not concerned with optimistic outcomes but about a possible life for one's future, I would like to offer some guidance as to how anthropologists might further this research in order to situate hope as a biocultural process via future data collection that could test this hypothesis.

First, Beatriz, a 22-year-old client at KP, whose parents help her pay for five therapy sessions per week, relays to me that the best thing medical professionals can do is, “be supportive and don’t ever tell a person what they can’t do.” Beatriz was injured two years prior, and so may fall into this optimistically hopeful category that Daniel lays out. However, her recommendation, as well as that of many at KP, that medical/health professionals not close off their patients’ hopes, is important as it communicates what patients need based on where they are rather than where physicians and other health professionals would like them to be. However, even innocuous statements like Armando’s can be interpreted as foreclosing hope.

A recommendation given by Sam and Jamie was for health professionals to, as Jamie articulates, “be more understanding...don’t do less work, but figure out what is suitable to the person.” I believe this desire to be seen as a “person,” and as an individual not capable of being generalized into a category (i.e., “paralyzed,” “paraplegic,” or “quadriplegic”) is reflected by what patients and clients receive at KP. As mentioned above, what separates KP staff from other health professionals is the sociality inherent in ABT, where patients and clients engage in 2-hour sessions with KP staff, having conversations and building relationships with one another – a dynamic atypical with other health professionals, or even compared to other rehabilitation modalities.

This notion of relationality is similarly discussed by James and Kevin in Chapter 6, where James refers to pwSCI as “gimps” as a way of both reclaiming this slur and using its affective weight to make a larger point, and Kevin argues that a mother’s attempts to “teach” her son to be quadriplegic is work only performed by him and other quadriplegics. Repeatedly, sociality emerges as an important means of both narrative re-envisioning as well as of affective

transmission. The one way to truly affect one another is to be in relationship with them – which is what is enabled at a place like KP.

For future research, first, I believe that capturing where rehabilitation participants exist on this narrative process is primary. Through utilizing experience-near methodologies, researchers may contextualize a patient's inner life, attempting to uncover how one conceptualizes his or her goals, we may discover the importance of recouping physical functioning as well as one's expectations for doing so. Much like Jessica initially believed she would walk again and transitioned to "acceptance" regarding the fact that she likely would not, I believe that situating an SCI rehabilitation participant, and whether they maintain hope as an optimistic outcome or as an Ingoldian acceptance of ambiguous outcomes, may likely coincide with where they exist on this spectrum.

Second, I hypothesize that measuring pwSCI sociality may similarly indicate one's internal emotional and affective world. As James' story in Chapter 6 indicates, exposure to those whose situations arouse sentiments of sympathy and pity – while indicating the dominance of ablenormativity – may also serve as a means of feeling one's way out of the spiral of depression that often characterizes pwSCI. As such, might lack of exposure to people with disabilities be associated with a decreased mental health status?

Third, as I discussed in Chapter 4, pwSCI are enveloped in a double bind in which they are enabled by bureaucratic supports (such as via Medicare or veterans' insurance programs) while being socioculturally fed pessimistic messages about their recovery outcomes. Rather than closing off hopes of recovery, what might occur if pwSCI were granted a period to practice ABT, which is currently the only therapy modality that specifically challenges SCI patients to perform movements both at and beyond their physical functioning? Rather than expecting blind/bare

compliance, might instituting this form of care also support pwSCI patients to physically, mentally, and affectively test and find their limits?

As Daniel and Jack argue, patients come to a form of “acceptance,” which they, along with Carmen and Jared, argue can support recovery outcomes. Is it possible that this form of acceptance is only attainable through practicing therapies that can reveal the pace of recovery in a way no physician can explain to a patient? Indeed, insurance coverage already separates patients by how affordable such resources may or may not become. Might democratizing such resources and possibilities support the mental health of pwSCI who are often given a license to do nothing?

Fourth, future research should explore the narrative and affective dynamics of how such normative standards play out in consultation rooms between doctors and patients. The difference between physicians and KP staff was often social closeness. Within traditional standards, patients are expected to accept their situation to find new activities worth performing rather than focusing on what physicians consider to be futile attempts to recover functional mobility. However, KP staff similarly held such patient expectations as burdensome not only to their quality of life, but also to the productivity of rehabilitation sessions. Yet, as KP staff formed close bonds with rehabilitation participants, such expressions were received as informed and meaningful recommendations.

Indeed, physicians, some of whom only met patients a couple of times, might only see a patient through their generalized identity as an SCI patient, requiring them to generalize SCI and project such recommendations onto their patients. Much like KP staff, who illustrate how their training fails to prepare them for the truly unpredictable nature of SCI, physicians seem to place

immeasurable weight on what is possible based solely on a diagnosis rather than assessing the patient presented to them.

As a fifth, yet related, focus, I hypothesize that ABT functions under the same logic of traditional therapy modalities, which Rembis (2013, 113) argues promote a narrative of “overcoming” and even “passing” as able bodied. Such desires stem from wanting to be an individual before an identity category – such as in Rembis’ article where one would like to be seen as an ‘athlete’ before being defined as a ‘one-armed athlete.’ Despite the narrative tension between ABT and “traditional” rehabilitation therapies presented in this dissertation, I argue that the difference only lies in how recommendations are received and exist within a person’s life.

Testing this hypothesis could entail conducting: (1) surveys measuring the attitudes therapists have regarding recovery and its desirability; (2) interviews with therapists to investigate the goals they have for their patients; or (3) analyzing patient-therapist interactions for how goals are practiced on the therapy floor. I believe findings would discover negligible differences between ABT and ‘traditional’ therapists as I believe many of the differences stem from the ABT modality itself rather than moral or ethical differences in the individuals practicing it.

Recommendation 6: Conceptualizing and Measuring Hope

Sixth (and last), I hypothesize that hope is a biocultural phenomenon that can be illuminated by analyzing the therapeutic interaction. This dissertation presented various interactions wherein rehabilitation participants had the opportunity to place their bodies in various positions that they desired – especially in standing or walking positions. I believe that such movements of the body were crucial in supporting the amounts of EE incited through interactive rituals – such as joking – at KP. In order to do this, I believe understanding where a

patient exists on the “hope” spectrum (the first recommendation above) will help identify the nature of the “hope” he or she has. Is their hope about optimism, or about holding the future in suspension long enough to trust one’s therapist to lead the way?

I also believe that the nature of one’s hope rests on one’s mental well-being, which I believe to be influenced by the second recommendation above on SCI sociality. As Molly Bloom (2020, 118) argues, a robust “disability community” among pwSCI may potentially create new subjectivities past the narratives of “overcoming” and “license to do nothing” that ablenormative power structures impose on pwSCI. Thus, investigating the links between disability sociality, mental well-being, and biocultural hope may offer new ways of thinking about rehabilitation practice and recommendations. ABT may be the modality best suited to institute such practices given its inherent sociality.

To illustrate what I mean by ABT’s inherent sociality, I take a story told to me by an SCI advocate during the course of my research. The advocate, Tim, explained to me that proving physicians wrong is exemplified by the story of Todd Krieg, a man who attended an ABT center in Carlsbad, CA – in fact, at Project Walk, the very first ABT center. There, Todd met his wife, a physical therapist there, and, despite doctor’s assertions that he would never be able to conceive, they now have two young children (Basheda 2017). Krieg and his wife tell a story of how they met at a bar organized by some at the rehabilitation facility.

This story exemplifies something characteristic about ABT centers (such as KP): an environment where long-term relations are encouraged and common among and between therapists and clients. Todd Krieg’s story also exemplifies something common among my participants at KP – instances where doctors described one’s new life as lacking any possibility for something one could have expected before injury. In this case, a sex life and natural

conception. This ABT culture goes a long way towards increasing mental and emotional psychological recovery for those who are, at least initially, mostly concerned with achieving some form of physical recovery. Future research should also explore the nature of such sociality both in and outside of rehabilitation facilities.

To investigate biocultural hope, future research might select longitudinal case studies. This would best be conducted in collaboration with a rehabilitation center with robust patient outcome monitoring. Monitoring would entail tracking of “hope,” mental well-being, one’s social well-being, and of physical outcomes/progress such as functional mobility and strength. Data could be collected at multiple sites in order to maximize sample size and thus statistical power of such analyses.

Discussion

In this chapter, I reintroduced the three-level framework from Chapter 2 to argue that the logical structures of difference created at KP differ from how rehabilitation is enacted there. These are clear instances where words fail, as the oppositional relation between ABT and traditional therapeutic modalities is more of a narrative distinction than an actual one. Additionally, I used literature from affect-theory-oriented anthropologists in order to situate the importance of affect, affective communities, and how affect is transmitted in order to argue that the process of ABT itself creates difference rather than KP staff practicing a truly distinct moral imperative (Newell 2018; Stodulka, Selim, and Mattes 2018; Yun 2021).

For instance, I’ve previously described how the moral imperative to take patients out of their chairs is seen as novel practice at KP. While this may be true of ABT, I believe the interactions inherent in ABT at KP offer rehabilitation participants to practice both embodied reorientations in ways they haven’t since their injuries as well as an opportunity to practice

narrative re-envisioning, each of which can only occur in relationship with others. Given that ABT is covered by few insurances except for Medicare – for which patients do not qualify until two years post-injury – mental and physical well-being might be supported by pursuing this particular therapy modality.

Thus, in this chapter, I distinguished between these narrative images (secondary level), the regimes of truth that support them (tertiary level), and ethical affective imperatives (primary level) in order to show that any one of these levels can create large differences in experience. However, the social structural dynamics of ABT at KP, which relies heavily on donor-supported subsidies to assist self-pay clients, stems from its ethical affective history embedded in the Dardzinski Method and its non-profit origins – which by definition attempted to institute rehabilitation outside of normative methods.

However, a consideration I'd like to deliver is that, at KP, there are current talks of reducing therapy sessions from 2 hours to one hour in order to accommodate more patients and turn a greater profit. I believe this is enabled through how the narrative image places weight on the ethics of ABT care. Could it be that reinforcing the distinction between ABT at KP and “traditional” therapy at a facility like the VA could lead to KP's leadership conforming back to the traditional model, all because they believe the strength of their narrative image? In the next chapter, I summarize this dissertation while also leaving some concluding remarks about the research undertaken at KP.

Conclusion

This dissertation's results evolved past the original research questions, which sought to understand how the SCI apparatus functioned, the process of caregiving, and the emotionality of SCI experience. Namely, the three-level approach articulated throughout this dissertation came after these questions' formulations, complicating the "emotion" focus of my third research question. Additionally, the SCI apparatus revolved around rehabilitation staff at a single site as other more integrated institutions refused to participate. As a result, my data focused on specific cases and scenarios and was less integrative. However, it did offer an opportunity to develop the three-level approach articulated throughout.

This dissertation used various qualitative methods to investigate the nature and functions of the SCI apparatus, which entailed rehabilitation staff, insurance billing, the structure of the staffing of the rehabilitation floor, caregivers, pwSCI themselves, SCI researchers and advocates, and physicians of pwSCI. Only physicians of pwSCI were not directly spoken to as many were either inaccessible or refused to partake in this research due to organizational responsibilities. This dissertation also explored the nature of care and caregiving both between caregivers and pwSCI, and between pwSCI and KP staff. Lastly, it explored the emotional and psychological experiences of pwSCI in order to fully investigate how they interact with the sociality at KP, both internally and externally.

This dissertation touched on several themes relevant to these research foci. First in Chapter 4, it used patient case studies in order to illustrate how relevant identity markers modified both SCI and rehabilitation experiences. Thus, recognized identity markers such as

veteran status, time since injury (as it relates to Medicare qualification), as well as injury level (i.e., being recognized as a type of injury, both locatable on the spinal cord and determined to be complete or incomplete) each deploy a given set of possibilities for pwSCI. No individual is completely denied rights and resources. However, as in the case of Tom, being designated a totally injured individual confers certain benefits, especially when paired with comprehensive insurance coverage such as Medicare, or Tom's VA-funded Tricare insurance.

The biomedical apparatus vis-à-vis pwSCI must bureaucratically define and designate bodies according to a rational, relational set of standards. This is the "regime of truth" I refer to throughout this dissertation. Combining the way Good (1994, 68) links biomedicine with a set of cultural paradigms that organize reality, with how Boyer (2008, 39) situates expert knowledge according to how it practices a specific "semiotic-epistemic" expertise, the regime of truth designates the regime of biomedicine (specifically, vis-à-vis chronicity and disability) as constraining notions of truth, often in dichotomous terms within which medical practitioners and patients are made to operate. This is consequential to patient experience and care acquisition.

Case studies like David are crucial for clarifying how his initial designation (as a complete injury due to the visual extensiveness of his initial injury) contrasts with his subsequent one (being redefined as incomplete due to his actual ability to recover functional mobility much more rapidly than predicted). As David explained, his initial injury looked like an "explosion," which his physicians reasoned made his recovery unlikely. But what is revealed in this process is the very process of definition and its consequences. Such consequences are communicated by pwSCI through rhetoric surrounding "hope," where physician designations can modify the kinds of possibilities available to pwSCI. For example, being determined as "too good" to have goals, which is code for being disqualified from continuing rehabilitative care.

This dissertation then, in Chapter 5, presented various dichotomous categories in order to outline how KP staff and rehabilitation participants construct moral categories that place KP and its ABT philosophy contra traditional therapy modalities. In addition, I outline how the logic of Medicare billing at KP also causes rehabilitation to be deployed in certain ways, consequential to all who attend rehabilitation sessions at KP, including those self-pay clients, some of whom pay out of pocket in order to avoid the constant oversight (i.e., the imposition of audit culture) into their lives. This chapter ultimately argues that the narrative of ‘ABT versus traditional therapy’ merely intensifies differences that are much more modest. This is evidenced by how KP staff regularly suggest that rehab participant be more realistic and accept that the severity of their condition is much more stable than patients/clients optimistically hope. Rather than positioning KP staff as just as hopeless or nihilistic as SCI physicians, I argue that this similarity between the two suggests that what makes the difference is simply sustained exposure.

Thus, in Chapter 6, I outline how joking and exciting social interactions can deploy more effective therapies at KP. This begins to theorize how a biocultural approach to hope may have some therapeutic impacts that might be leveraged. In Chapter 6, I also outline tangible ways that “acceptance” can lead to better and more effective therapies for pwSCI. While this recommendation, early on in their injuries, seems to produce a sense of frustration, resulting in motivation to prove these prognoses wrong, I argue that its ability to be developed in intense long-term interactions with rehabilitation staff at KP recontextualizes this recommendation. Instead of listlessness, this recommendation serves to hold hope in suspension.

I describe this further in Chapter 7, where I distinguish between hope as an optimistic notion versus hope as one that promotes a general outlook on the future as suspended and inherently uncertain. This inherent uncertainty may enable SCI rehab participants to let go of

certain anxieties in order to make room for KP staff to construct useful therapies that they might pursue. Thus, in many ways, KP staff are able to accomplish what physicians initially may have wished for their patients – for them to find a life from the confines of a chair. They simply may have neglected the possibility that this life could still be pursued in therapy, which, while not necessarily oriented towards recouping bodily abilities, still engages the body and acknowledges pwSCI as embodied persons despite their injuries.

This dissertation outlined various images of thought (legislative tertiary level). These included Medicare insurance logics, the Dardzinski Method, and various dichotomous concepts such as active:passive::long-term:short-term::relational:bureaucratic::hopeful:hopeless. Each of these are categorized as images of thought because they deploy a given regime of truth: they imply certain truths about the world (e.g., Dardzinski Method sees bodily ability as similar to the physical development of a child) while instilling a certain identity in those involved (e.g., the activity of ABT as a hopeful modality became increasingly glossed in moral terms, which tended to reinforce its status as a “better” therapy modality).

What did these images of thought enable? They enabled the various utterances and assertions covered throughout this dissertation, such as David’s assertion that his own motivation was the “game changer” in his ability to recoup functional mobility. The activity of ABT reinforces the idea that those who remain active and conform to this ethical prescription will derive greater benefits from it. Similarly, Jessica’s assertion that she “would not wish” her injury on anyone, including her enemy, is enabled by her understanding that SCI is a transcendental condition to which few other injuries can compare. Thus, James’ story about being affected by a “kid” in a worse position than he touches on SCI’s transcendental position but helps complicate it. Rather than SCI being absolutely transcendent, pwSCI are in actuality accustomed to their

double bind position (quotidianly ordinary but socially deemed extraordinary), and in instances of comparison, are able to shake themselves out of the absoluteness of transcendental-SCI by being affected by another.

This latter example provides an instance where all levels of analysis are evident. Thus, rather than being strict, separate levels, instances of communicated affectedness can indicate moments when normative ethical affects are challenged. In this case, James' experience challenges the norm that SCI *should* be an extraordinary experience. This reveals how sustained emotional interactions can manifest difference. In other words, through its repetition – the repetition of the therapeutic encounter – difference emerges. Difference in how one understands one's injury and recovery process, and difference in how one proceeds with therapy. Rather than believe in the stagnation of bodily recovery, rehab participants can at least hold in suspension any belief – whether pessimism or optimism – in order to make the future possible and something with which they can again be engaged.

This dissertation centered hope because its biocultural weight was powerful on the therapeutic floor. However, other words could have been used. Perhaps 'motivation,' 'endurance,' or 'resilience.' But given the use of "hope" at KP, and its ambiguous, somewhat superfluous definitions, I found it to be most appropriate to use.

Institutions have unifying ethics. In this dissertation, I illustrated how KP's unifying ethics include mechanisms for promoting joking in ways that increase motivation and emotional energy among rehab participants and KP staff. I also illustrated ways that KP makes room for audit culture to fully express itself – i.e., through its bureaucratic history (set up as a therapy modality contra traditional therapy) that grants pwSCI recourse in pursuing rehabilitation outside of those institutions that defined them as incapable of recovery. Rather than contradicting the

logic of evaluation, KP has created mechanisms where it can both sustain those same avenues while creating a morally relevant, donor-supported structure which together both comprise two side-by-side systems of income-generation.

The point here is that, just as KP staff were not different in kind from other rehabilitation staff elsewhere, nor is KP different separate from its bureaucratic normative structure. In other words, rather than KP having some inherent identity of competence that makes it qualitatively better than traditional therapy modalities, I argue that its structure of 2-hour sessions, sustained interactions, and “thick sociality” (to borrow from Bloom 2020) are the very mechanisms that makes it so special. Without these, it may be less distinguishable to those therapy modalities its staff and rehab participants seek to critique.

This is relevant to consider as several KP rehab participants have, since concluding the research, told me that the non-profit’s leadership is considering reducing sessions from two hour to one-hour sessions. In addition, prior to her departure, the former Operations manager, Katie, told me that KP leadership was considering shifting from a non-profit to a for-profit structure. These considerations, if executed may create immediate changes in both how KP operates on the therapy floor as well as how it deploys various moral arguments.

In thinking about how to close this dissertation, I would like to look to the future and consider how the way we define ourselves can create limitations in our ability to act appropriately. Given the potential changes to take place at KP, I wonder how the image of thought, if dogmatic enough, could bring about reduced awareness of the unintended consequences of certain actions. In this case, how shifting several core institutional (along with its moral) mechanisms would likely shift the core aspects of how that institution functions. As I’ve argued throughout this dissertation, the interactive nature of ABT culture at KP goes a long

way towards increasing recovery for those who are, at least initially, mostly concerned with achieving some form of physical recovery.

Given these findings, it could be easy to assert a linear development of therapies where: a medical establishment defines a limit; this limit is exceeded by patients practicing a “divergent” therapy model that leverages bodily- and neuroplasticity; and that this must necessitate a rethinking of the kinds of therapies that such established centers like the VA offers its patients. However, the three-level approach guides us in a different and applied direction. Instead, we see that the kinds of rationalizations spoken by all interlocutors inhabit different ontological spaces because of their different historical trajectories.

Given this, future research might entail a few different trajectories. First, research should seek to integrate pwSCI who do not attend rehabilitation, which would serve to complicate some of the conclusions drawn, such as how hope exists and shifts during the rehabilitation process. Second, elaborating on discussions in chapter 7 about how to proceduralize hope, future research should seek to identify which ontology of hope patients inhabit, exploring its links to patient outcomes regarding mental health, secondary conditions, and functional recovery. This can be done through longitudinal data collection via epidemiological surveys that seeks to validate the use of hope as a predictor of other health outcomes, having some strong application in clinical and therapeutic settings.

Additionally, this research can offer some strong applied contributions both to rehabilitation practice in general, and to KP specifically. It is relevant that the VA offers long-term care for veterans, but it exists in a system that must prioritize care for thousands of veterans. At KP, a facility that serves 55 unique clients per month, it is feasible to employ the kind of resource intensive therapy like ABT. However, it may not be feasible to do so at facilities like

the VA—as they’re concerned with capacity for the astounding number of patients that cycle through their clinics. Similarly, the local hospital, as an acute care hospital, specializes in immediate trauma. While it has facilities that serves outpatient rehabilitation patients, it also serves the entire Tampa Bay region, limiting its ability to serve too many clients long-term. Thus, recommendations that suggest implementing ABT in these settings would be inappropriate and short-sighted.

In this light, utterances by those facilities’ administrators simply reflect organizational ethics. Instead of removing all hope, these recommendations are embedded in what they deem possible and the justifications that result. Alternatively, KP can execute such an ideal form of care only through a nonprofit, donor-supported structure. Regarding rehabilitation practice, findings suggest recommendations towards cross collaborations between these types of facilities. PwSCI might best be served by a coalitional dynamic between KP and surrounding hospitals. As of right now, many people hear about ABT facilities by word of mouth – including sometimes from their physicians – but there is no structural connection between them. Comprehensive resources and supports that offer long-term education for pwSCI and their families and caregivers would provide long-term care, which many at KP identified to be missing in their lives (hence KP’s impact in their lives).

Regarding pwSCI and their caregivers, these findings promote a different set of recommendations. For pwSCI, it suggests that finding a culturally consonant space within which to operate may be the most beneficial to biocultural, as well as psychosocial, recovery. Indeed, many of KP’s rehabilitation participants indicated that they were highly active individuals prior to injury. Thus, KP’s philosophy may be easier to integrate into the lives of those whose own exercise philosophies align with theirs. This hypothesis of course needs to be substantiated.

For caregivers, these findings suggest that they might benefit from more socially inclined therapy modalities such as KP. However, in order to adequately do this, they may have to bracket their own desires for their loved ones in order to promote more quality-of-life outcomes. For instance, might Caleb's daily situation be improved by using an indwelling catheter? Caleb's mother indicates being hard on Caleb in order to prepare him for life after she is gone, but to what extent might this serve to ignore tangible ways that Caleb's life may be more fulfilling? Similarly, this hypothesis must be explored and tested in future research.

Furthermore, regarding training of physical therapists and other KP staff, findings suggest that robust training in patient communication would be greatly beneficial. Indeed, formalizing the social competencies learned by KP staff – such as by not telling patients what they “should and should not be able to do” on account of their injury would go a long way towards training new staff members in the competencies of the realities of SCI.

While pwSCI narratives criticize the privileging of traditional therapy modalities, this approach clearly creates resistances that would never have occurred otherwise. After all, patients' attitudes and resistances are situated against how they interpret their physicians' prognoses. Thus, integrating rather than solely critiquing the ABT modality could serve to include SCI rehabilitation participants under the purview of the robust data collection and management that institutions like the VA are best positioned to track and analyze vis-à-vis participant outcomes. Put another way, integrating long-term dimensions in de facto short-term care models (i.e., where physicians treat patients in short, purposeful encounters) would help create a continuity in care that my participants often felt was missing in their healthcare experiences.

To promote hope in these medical settings, a reflexive approach to clinical encounters could assist broader outcomes by drawing in disparate stakeholders that are often positioned as external to bureaucratic rationales. For instance, my experiences attempting to collaborate with the VA hospital (which is the largest SCI care hospital in the entire VA system) was prohibitive bureaucratically – I was told that physicians and VA staff are generally not allowed to participate in external research projects not directly conducted and controlled by the VA. Hence why I could only interview one VA administrator. Taking the time to integrate – in whatever manner fits with bureaucratic rationales – external partners would help to cross pollinate ideas and confidence across all kinds of therapies in Central Florida.

Furthermore, I believe presenting my findings on the two ontologies of hope (object versus process-oriented ontologies) could help situate patient perspectives for physicians and healthcare providers. Given that my data interrogate how pwSCI interpret their own experiences (e.g., where they see physician recommendations as promoting a pessimistic resignation to their conditions), I believe that providing understanding on these ontologies of hope to physicians would enhance their understanding of the kinds of stances their patients have. Such training could help facilitate collaborative clinical relationships, benefitting all involved.

In addition, I wonder what would happen if KP shifts its non-profit structure to a for-profit. Since completing data collection, KP has begun charging extra for its services, even for patients whose insurance pays for sessions. If it were to transition to a for-profit structure, I would predict that KP would look nothing like the VA or the local hospital, as these institutions have very specific goals and capabilities, as discussed above. KP would be capable of serving its community, but in order to maintain its main strengths, I would recommend retaining the two-hour session as this intense interactive component is most beneficial for its patients and clients.

Reducing therapy to as little as an hour, minimizing the number of times a week patients and clients can attend, and charging more for its services would relegate it to its most privileged participants. It would then be difficult to promote its services as a hopeful alternative to traditional modalities.

Lastly, this dissertation has engaged with disability anthropology in various ways. As described in chapter 1, the impairment-disability divide is totally upended when dealing with a population that hopes for a cure while also fighting for inclusion. These are not mutually exclusive pursuits. As such, despite disability anthropology's shift away from rehabilitation settings, this research designates the rehab floor as a moral laboratory where affects and sociality can be exercised leading to radical transformations in one's embodiment and ethics. Indeed, rehabilitation is imbued with copious mental and affective energy, necessitating research dedicated to exploring these transformative implications.

Additionally, the three-level approach used in this dissertation offers a new model to situate anthropological theory. Rather than claim broad universal phenomena, which have all been critiqued copiously (cultures do not progress in uniformly evolutionary trajectories; nor does affect comprise a primitive, universal set of species-specific potential) this approach generalizes a methodology for approaching human cultural processes. Anthropologists have long denoted how human activities, behaviors, and utterances can often be in contradiction to one another. By situating these in their own ontological realms, this approach promises to create useful engagements with ethnographic text. I also believe it can serve as a pedagogical tool to help students make sense of their own methodological and analytical toolkits.

The next step for this three-level approach is to write a manuscript pairing it with a specific ethnographic vignette. This will allow other anthropologists to apply this three-level

approach to their own ethnographic contexts, which will help draw out some of the benefits and limitations of such a vertical three-level approach. While its specificity makes it easily applicable, it still risks becoming a Geertzian “impeccable depiction,” being as “coherent as a paranoid’s delusion.” Nevertheless, I believe this kind of explicit, integrative theorizing (which places political economic programs in conversation with affect theory) will help move the field forward by tearing down some of the distinctions between the subfields – something attributable to many Deleuzian anthropologists.

Despite what changes may come, KP currently allows rehab participants to engage in sustained communication with rehabilitation centers. They end up working out for themselves ways of dealing with their injuries. In many cases, patients and clients come to accept their bodily status, while also accepting the ambiguity of their situation. KP provides a rare opportunity for individuals to try out a different way of engaging and existing in the world no longer dependent on others defining them as extraordinary. Finally stepping outside of secondary rational utterances and the regimes of truth that made them possible (perhaps even inevitable), pwSCI at KP are enabled an opportunity to engage, live, and feel their world around them. To joke and play – even if they end up occasionally being offended. Isn’t that just called living?

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Appendix A: IRB Approval Letter



EXEMPT DETERMINATION

September 21, 2021

William Lucas
[REDACTED]

Dear Mr. William Lucas:

On 9/20/2021, the IRB reviewed and approved the following protocol:

Application Type:	Initial Study
IRB ID:	STUDY003051
Review Type:	Exempt 2
Title:	The Biocultural Assemblage of Spinal Cord Injury Rehabilitation
Protocol:	• LUCAS_HRP-503a - Social-Behavioral Protocol Template_5.1.20 - 9.15.docx;

The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BullsIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

Sincerely,

Jennifer Walker
IRB Research Compliance Administrator

Institutional Review Boards / Research Integrity & Compliance

FWA No. 00001669
University of South Florida / 3702 Spectrum Blvd., Suite 165 / Tampa, FL 33612 / 813-974-5638

Page 1 of 1

