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UNIVERSITY OF CALIFORNIA SAN DIEGO

Against the Ropes: Fighting for the Self against Parkinson's Disease
in a San Diego Boxing Gym

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy

in

Anthropology

by

Julia K. Sloane

Committee in charge:

Professor Steven M. Parish, Chair
Professor Suzanne A. Brenner
Professor Colin A. Depp
Professor Douglas W. Hollan
Professor Bonnie N. Kaiser

2022

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The dissertation of Julia K. Sloane is approved, and it is acceptable in quality and form for publication on microfilm and electronically.

University of California San Diego

2022

Dedication

To Thomas and Barbara Sloane, my dearest grandparents, and Calliope, my muse.

Epigraph

The Lesson

I keep on dying again.
Veins collapse, opening like the
Small fists of sleeping
Children.
Memory of old tombs,
Rotting flesh and worms do
Not convince me against
The challenge. The years
And cold defeat live deep in
Lines along my face.
They dull my eyes, yet
I keep on dying,
Because I love to live.

Maya Angelou

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Vita

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Major Field: Psychological and Medical Anthropology

Abstract of the Dissertation

Against the Ropes: Fighting for the Self against Parkinson's Disease

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by

Julia K. Sloane

Doctor of Philosophy in Anthropology

University of California San Diego, 2022

Professor Steven M. Parish, Chair

This dissertation presents a person-centered ethnography of the lived-experience of Parkinson's Disease and the use of boxing as a healing modality to slow illness progression and empower a positive aging experience. Specifically, it explores how elements of agency, relationality and embodied experience are implicated in processes of the self and paradigms of personhood in the United States. By entering the world of a San Diego, California boxing gym

that trains people with Parkinson's, this work advances an anthropological understanding of how individuals employ cultural affordances to reckon with inconsistencies in self experience.

Through aligning biographical narratives with the culturally popular metaphor of the fighter, individuals are able to embody an ethical subjectivity that encourages engagement in physical, mental, and social health despite the trajectory of degeneration that their illness proposes.

Ritualized embodied learning actively binds the feelings of exhausted effort, and fatigued muscles to a sense of ideal personhood, and accomplishment; while the ethos of the gym and community of fighters create a meaningful sense of normality and belonging that enriches daily life.

Chapter 1 Into the Ring

“It’s a heroic battle that all of us are fighting, and we should be proud of ourselves.” - Blinder

1.1 Setting the Scene

Moxie¹ was looking for another exercise program to add to her regime. An hour and a half of boxing each morning wasn’t enough for her. “This is my job now,” she explained. “It’s the only way to stay ahead of it.” A bell rang signifying break time was over and the gym came alive once more with punches, lunges, speed bags and sparring. This may sound like the usual sights in a boxing gym but the fighters attached to these movements were anything but typical. The “it” to which Moxie referred was Parkinson’s Disease, and intense forced-rate exercise has been identified as a highly effective and non-pharmacologically based intervention to delay illness progression (Ghaffar et al. 2020, Hoime, et al. 2018). Twice a day, this boxing gym provides 90 minute training sessions oriented around people with Parkinson’s- from the newly diagnosed to the wheelchair-bound. Each one had a point to prove: “I’m still here. I’m still fighting. I’m still me.”

Like almost every other fighter in the program, Moxie had never previously considered herself a boxer. She’d been athletic and enjoyed exercise. She even took partial credit for Balboa Park outlawing rollerblading after she and her friends made it a habit to speed through the scenery in their youth. Boxing, though – the act of physically fighting was unique to her Parkinson’s life. Moxie was one of a group of female fighters. Many of the women would laugh

¹ All names are used throughout the dissertation are pseudonyms of boxers’ nicknames.

at how unexpected this practice was before expressing deep gratitude for the role it played in their treatment and well-being. They shared that something about punching a bag or a padded person created an immediate sense of release that was not found in other activities or pharmaceutical interventions. It empowered them physically, psychologically and socially.

The gym used different types of games to incorporate cognitive and vocal elements into boxing workouts. One such game required participants to yell “get off my bag” to another boxer before switching places and executing a series of punches against the heavy bag. While the best-known symptom of Parkinson’s is tremor and a loss of motor control, a host of other symptoms make up the profile of the disease, and each individual has a unique collection of them. One common experience is weakened vocal chords, leading to a soft voice that can be difficult to understand drastically impairing communicative abilities and confidence. Each class ends with a loud call and response. Fighters circle up and extend a fist into the center.

“Who are we?” yells Coach.

“Rock steady!” answers the group.

“What do we beat?”

“Parkinson’s!”

“Rock steady on three! One, two, three!”

The fighters raise their fists triumphantly into the air in unison while shouting out: “Rock steady!”

Coach ends the round saying, “Great work out today. Give each other some love and thank our volunteers for their help.” Fighters bump each others’ fists, thank one another for the support and extend congratulations for the accomplishments. It truly is an achievement worth celebrating, and the atmosphere of the gym is full of gratitude for the opportunity to engage in battle with their faceless opponent. For the fighters, the workout has been physically exhausting and spiritually uplifting.

Multiple individuals expressed the view that keeping active was the only way to “stay ahead of it” referring to disease progression. Scholars in Physical Therapy have discussed the importance of mixing cardio, stretching, and meditation for effective disease intervention (Ellis and Rochester 2018). Moxie would later learn that she’d been *over*-exercising with too much cardio which had temporarily exacerbated muscle stiffness and pain. Parkinson’s creates stiffness in the body, which stretching can alleviate. It also disrupts the regulation of dopamine eliciting bouts of anxiety that benefit from targeted stress reduction. Dangerously, many anti-anxiety medications increase the risk of falling (Huang, et al. 2012) which is a particularly significant concern for this community making non-pharmaceutical interventions highly desirable.

Beyond the documented physical benefits, however, the gym community has also become a fictive family for many of the fighters. Seeing people who are farther along in disease progression and still engaging in their social lifeworld reinforces the continued value of social capital despite illness. It may not be literal kinship, but the knowledge and shared context around lived-experience of Parkinson’s is profoundly encouraging and humanizing. To quote one boxer, “it makes me feel like normal again, like a normal person.” Additionally, the years of accumulated knowledge benefit not only the more recently diagnosed fighters but those who are transitioning to a different stage of the disease. This can be particularly valuable for the women who are more marginalized in the Parkinson’s community due to their minority status and struggle to find gender-specific information. One of the female fighters claimed, “I’ve learned

more from the other female boxers than anywhere else.”² I will discuss the gendered dynamics of Parkinson’s further in chapter two.

This ethnography tells the story of a group of survivors who are experiencing a positive aging experience while living with Parkinson’s disease in San Diego, California. By joining a boxing gym that specializes in training people with Parkinson’s, these fighters are acquiring new methods of engaging in healthy and pro-social behaviors instead of withdrawing into isolation or submitting to the progression of the disease. By performing the culturally valuable traits of productivity and responsibility, they are demonstrating their continued ability to align with the dominant ethical conviction that one should take control over one’s own health and future.

I will begin the story by briefly introducing our challenger: Parkinson’s Disease. I will then situate the dissertation within the theoretical realm of neuroanthropology with an emphasis on the developing subjectivities of fighters and the embodied dynamics of agency and temporality that problematize the aging experience for people with Parkinson’s. Of particular interest will be the experience of women who face unique challenges as a minority within the Parkinson’s community. Following a description of the methods, participants and field site of this research, I will outline the chapters that follow.

1.2 The Parkinson’s Challenge

Parkinson’s Disease poses unique challenges to the experience of personhood making it a particularly interesting case for psychological and medical anthropology. Parkinson’s is the second most common neurodegenerative disease after Alzheimer’s Disorder affecting nearly 1

² While the disease pathology is not drastically different between sexes, the experience most certainly is and I will illustrate this in the following pages.

million people in the United States with around 60,000 new diagnoses made each year (Marras, et al. 2018). The disease increases in incidence with each year over the age of 50, with only 4% of diagnoses given to individuals who are younger (Williams-Gray and Worth 2016). Current figures place the likelihood of developing Parkinson's Disease at 1.5 times greater for men than women, though the prevalence increases at the same rate with age (Marras, et al. 2018). The disease unfolds over an average duration of 13 years (McNamara 2011:1). There are boxers in my study who have been living with Parkinson's for well over 15 years (one of who lives alone without difficulty). The appearance is astoundingly heterogeneous throughout the illness trajectory with each individual facing a distinct collection of symptoms (Lyketsos, et al. 2007). Hallmark indications include three prominent motor symptoms: muscle rigidity, changes in gait, and slowness of movement (bradykinesia), with a frequent fourth addition being a resting tremor in the extremities (McNamara 2011:1). A number of cognitive complications and non-motor symptoms accompany the disorder (Kalia and Lang 2015) and there are heightened risks in this population for developing comorbidities including certain mood disorders (e.g. depression, anxiety, apathy) and other psychopathologies (e.g. impulse control, sleep disorders) (Lyketsos, et al. 2007:121).

Dopamine replacement therapy has been the primary course of treatment for people with Parkinson's since the intervention first emerged in the 1960s. Despite extensive and well-funded research in multiple disciplines, nothing has yet surpassed L-dopa as the standard of care (Kim et al, 2017:296). This is particularly unfortunate, as L-dopa treatment causes a number of unpleasant side effects such as depression, mental fog, and gastrointestinal issues (Marsili et al, 2017). Dopamine is also difficult to regulate across time in a patient, causing constant fluctuations between "on states" and "off states," referring to blocks of time when dopamine is

effectively working in the body and times of impairment (Taddei, et al. 2017). This has a significant psychological impact on an individual's stable sense of self and behavioral expectations (Bramley and Eatough 2005). Beyond the constant disruptions to self-performance being personally demoralizing, this terrain places tension on family relationships when caregivers fear for their loved one's safety or feel frustrated by constant caregiving duties (Smith and Shaw 2017). In this way, Parkinson's effectively complicates multiple processes of the self and requires a hyper-personalized and holistic approach to combat.

1.3 Theoretical orientations

1.3.1 Neuroanthropology and the self

The core theoretical orientation of this work is from neuroanthropology, particularly an examination of the embodied disruption of performing a consistent and time honored sense of self – a version of one's self with which family, friends and community members are familiar. By familiar self, I am referring to the behaviors, attitudes and sensibilities that characterize not only one's engagement with the external world, but one's embodied sense of self-awareness and successful attunement to the impressions that one is making on others. Specifically, in this work I am exploring the mechanisms of skill acquisition and community engagement that reconstitute a healthy and successful sense of self for people aging with Parkinson's Disease.

The ontogenetic niche in and with which we are raised – including the sociocultural and environmental climate of a given time and the particularities of an individual's biology – influences developmental processes throughout life (Lende and Downey 2012). To develop properly, our minds and bodies expect certain external or environmental input at appropriate times (Rogoff 2003). We rely on culturally constructed knowledge to build a foundation for developing perception and awareness. Even as fetus in the womb, we are acquiring linguistic

sound patterns and foundations for the development of speech and perception. A baby’s cry will resonate with the familiar prosody of their mother’s voice (Mampe, et al 2009). The process of developing into a human with all of the nuances such a creature contains cannot be separated from the surrounding socio-cultural niche of the individual. Thus, we see culture influence biological development in very literal and observable manners.³

Anthropologists have been studying biocultural forces for long before the aphorism “biocultural” achieved much recognition within the field (or “biopsychosocial” models in the psy fields). As the anthropological tradition of inter-disciplinary collaboration continues, researchers have expanded methods for analyzing the deeply cultural nature of human development (Rogoff 2003, Worthman 2010, Hoke and Schell 2020). Neuroanthropological perspectives consider “social causation, the interactive model of development, biological embedding, and neuroplasticity and epigenetics” (Lende 2012: 193) for understanding a variety of complex human phenomena such as how socio-economic inequities are embodied in health outcomes (Dressler 2011, Lende 2012) and the emergence of psychotic symptoms (Myers 2012). Additionally, neuroanthropologists like Greg Downey have examined how skill acquisition can biologically influence or alter a person’s body and lived-experience. Downey has paid special attention to the manners in which individuals develop physical capabilities through training in rugby (2012), mixed martial arts fights (2007), apprenticeships in capoeira (2010, 2014) and more recently, respiratory patterns in SCUBA divers (2021). This anthropological approach to processes of embodiment attends to how components of an individual’s unique biological

³ The necessity of culture to human development and the diversity of possible sociocultural climates along with the variability of ecosystems which humans call home has led anthropologist Margaret Lock to propose the valuable concept of “local biologies” (2017) to help explain the drastically different accounts of biologically-oriented experiences.

profile, intersectional dynamics of stressors and socio-cultural and psychological factors interact to produce the human experience. “Rather than broad-based concepts like *habitus* or cognitive structure, neuroanthropology focuses on how social and cultural phenomena actually achieve the impact they have on people in material terms” (Downey and Lende 2012:31).

In this dissertation, I apply an adapted neuroanthropological methodology to analyzing the experiences of my research participants, who are hyperdiverse in terms of their embodied histories. This ethnography considers how developing skills in boxing and bodily control can cultivate a sense of embodied capital that allows fighters to perform a version of their selves consistent with personal histories and aligned with relevant cultural ethical discourse. Embodied capital refers to the physical, mental and perceptual ability to successfully carry out an activity (Hay, et al. 2021). It can be literally measured through quantitative techniques (e.g. neuropsychiatric evaluations, two-step test, Timed Up and Go test) and the medical records of people with Parkinson’s are filled with these data. This ethnography seeks a quotidian view of how these measurements and the pursuit of improved measurement outcomes influence the subjective well-being and lived-experience of individuals in practice. An additional aspect of embodied capital that emerges in this research is the phenomenological ability to temporarily gain dominion over the internal space that is often occupied by Parkinson’s through the practice of boxing and physical activity.

Self experience is deeply entwined with a moral valence that influences behavior, subjective experience, and notions of personhood (Parish 1994). Mainstream discourse in the United States emphasizes an individualistic agent responsible for their own welfare as key values (Becker 1997, Kauffman 2011). This expectation seriously complicates the experience of people

who require accommodations to engage in acts of social personhood, such as individuals with serious health impairments (Hay 2010) and advanced ages (Lamb 2014). Little public recognition is given to the challenges of living with aging bodies regardless of health status, and individuals with Parkinson's stumble through more and less expected changes to their embodied experience, such as muscle speed and strength or memory recall. Anthropologists have been careful to distinguish the different levels of self, from that of the experiential self to the objectified self or person (Hollan 1992). This work considers the dynamic interplay between these two as the disrupted experiential self encourages a manipulation of public performance and re-orientation to the self as a historically and socially situated object in each moment. This fluid and active nature of self experience is emphasized by Hollan's use of the term "selfscape" to account for "both the intraself and extraself terrains that the self system simultaneously maps and represents during the course of a day and night" (2014:182).

Recent anthropological accounts of being an older adult in today's world elucidate spheres of influence on the selfscape such as social changes and loneliness patterns (Malkki 2015), obligations of care-provision by older adults (Yarris 2017), culturally-acceptable behaviors and expectations (Lamb 2014) and dynamic impacts of globalization (Fry 2009). Each of these areas affect my group of interlocutors in unique ways depending on their personal positionalities. Structural classifications such as gender, occupation and age are also deeply influential to the technologies of self used by my participants to effect a subjectively successful transition into life with a neurological malady. According to Foucault, technologies of the self "permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or

immortality” (1988:418). I am attending here to boxing as a cultural affordance employed by older adults to retain a sense of control over their selfscapes while caring for Parkinson’s amid an evolving landscape of aging in the community (as opposed to institutional care).

1.3.2 Subjectivity, Agency and Temporality

Subjectivity has a long history in anthropology and is subject to what Anthony Giddens has termed “dual hermeneutics” in which lay uses obscure the social science definition of a term (Giddens 1976 cf Finke and Sökefeld 2018:1). Here, I am following Ortner’s classification and using subjectivity to refer to “the ensemble of modes of perception, affect, thought, desire, fear, and so forth that animate acting subjects. But I always mean as well the cultural and social formations that shape, organize, and provoke those modes of affect, thought, etc.” (Ortner 2005: 37). I am particularly concerned with how practices afford the embodiment of culturally dominant ideals of productivity and independence. Ethnographic research with people with Parkinson’s contributes to this literature by foregrounding the problematic experiences of temporality and agency in maintaining an ethical subjectivity.

Parkinson’s disrupts familiar quotidian rhythms. Time seems to speed up while the person slows down and struggles to keep pace. For productivity-oriented North Americans who have reached high levels in their careers, slowing down is a tremendous challenge that is potentially devastating to the self-image. Even in retirement, individuals have big plans to contribute to their families, communities, and self-growth, all of which are complicated by the appearance of Parkinson’s (Valcarengi, et al. 2018). Additionally, being out of rhythm creates challenges to the empathic resonance that reaffirms a person’s humanity throughout the day. As Becker observes, “when disruption occurs, the temporary or permanent destruction of people’s sense of “fit” with society calls into question their personhood, their sense of identity, and their

sense of normalcy” (1997:30). This notion of disruption of belonging is foundational to this dissertation and called upon throughout the text.

Parkinson’s Disease attacks the brain circuitry that neuropsychiatrists have implicated in the “agentic self,” which is responsible for planning, doing, searching for value and accomplishing goals (McNamara 2011: 12). When agency is impaired on a neurological level, the individual is idiosyncratically afflicted, left to maneuver asymmetric knowledge and the revelatory interactions that follow with no clear cultural script. Acclimating to agentic complications puts restrictions on temporality that significantly alter the relational self and the approach with which one engages in daily life activities. The cycle of symptom expression and medication throws individuals out of sync with behavioral expectations for someone without an invisible illness. The invisible qualities of Parkinson’s can confuse interlocutors and others whose reasonable assumption of a person’s capabilities are violated without clear reason. I explore how one’s inability to synchronize to social expectations can be experienced as a temporal affliction that problematizes interactions and empathic connections.

This work demonstrates the complex and unfolding dynamics of agency when aging with Parkinson’s and exposes the split between expectations and experiences of agentic performance than are not always aligned in daily interactions. Obscured visibility and general lack of knowledge about Parkinson’s disease can create embarrassing and isolating experiences for the person who does not consistently match familiar rhythms of social interaction and patterns of daily living. Misunderstandings and over-attributions of agency abound as individuals fill in inaccurate explanations for the unexpected gestures, slowed movements, lack of facial expression or swaying gate. Sara Lewis’ (2018) conceptualization of “inner agency” offers an explanation for how the re-engagement of agency as an intrapersonal experience promotes

subjective well-being among Tibetan refugees. I will demonstrate how the generation of inner agency is facilitated by boxing as an idiom of resilience among Parkinson's fighters and active in a model of healthy aging.

1.3.3 Gendered experience

Finally, this research has a focus on the experience of women Parkinson's fighters. The visibility of women within the Parkinson's community is low compared to the more frequently diagnosed men. Resources are often designed and oriented around men, and services offered to the community are largely attended by a majority of males. According to participants, women with Parkinson's can expect to be a minority in most groups and programs that they attend. Following a feminist phenomenological viewpoint, this work recognizes the dynamic socio-political landscape within which women are orienting their selfscapes and generating feelings of purpose. As I found through my conversations with female fighters, having the support of other women with Parkinson's provides validation and solidarity.

Beyond issues with visibility, clinicians are less likely to diagnose a woman with Parkinson's, rating the disease lower on their list of considerations than it is for male patients. Many of the women in my research had a complicated journey to diagnosis and struggled to find the appropriate care and support initially. They took the role of supporting one another very seriously and were pleased about the services that they were able to offer the community and themselves. In a culture that emphasizes independence, being able to maintain a level of self-care was a mark of pride. One female fighter expressed this saying, "men can't handle being alone. We're the caretakers. When a man loses his wife, he has to find another one. We can take care of ourselves." For the few single women of the group, they viewed taking care of themselves (and Parkinson's complications) as more important than finding a new mate to add to their list of

responsibilities. However, this lifestyle demands different avenues for socialization and support. At its heart, this ethnography considers the embodied experience of belonging as articulated through idioms of resilience that afford a practice of meaningful engagement with the self and community.

1.4 Methods

1.4.1 Participants and Interviews

Fieldwork began in earnest in November of 2019 – although I had been an irregular volunteer at the gym for many months before then and as of time of writing continue to do so. My methods included participant-observation at the gym and community events, interviews with fighters and their supporters and, group conversations situated around a topic related to living with Parkinson’s (e.g. depression, family relationships, disease management). While I don’t have an exact number of how many fighters I spoke with at the gym, events and during ring-side chats, I would estimate the number to be around 60 people (about one third of who were women). I conducted a series of five interviews each with eight of the female fighters. Interviews covered 1) background information, 2) PD profile and diagnosis, 3) social support and networks, 4) gendered experience and values and, 5) the COVID-19 pandemic and sheltering in place. Interviews topics one, three and four were semi-structured (Bernard 2006). The second and fifth interviews took a person-centered approach to elucidate the tensions that participants felt between their own experience and their expectations (Levy and Hollan 1998).⁴ In practice, the

⁴ Person-centered interviewing creates a space for the participant to reflect upon the medical experience through two perspectives. First, the interviewee acts as an informant describing the generalized pattern of events and standards. Subsequently (or in tandem), the interviewee shares their personal and unique experience which elucidates tensions between perception and lived-experience (Levy and Hollan 1998).

fourth interview regarding gendered experience and values contained components of person-centered methodology in the sense that comparisons were elicited between other family members and friends' experiences at times, though the emphasis was on the individual's experience itself. An additional five or six women attended female fighter conversations and a few more spoke with me around the gym. I conducted one to two interviews with five male boxers to follow up on topics discussed in group conversations or around the gym. I also conducted a single interview with three family members, the head trainer/ owner of the gym (though I had many side conversations and follow-up questions with him) and a second trainer at the gym.

Person-centered and semi-structured interviews were almost entirely conducted over zoom with a few in-person "socially-distanced" exceptions.⁵ These occurred on participant suggestions and were not seemingly related to the interview topics themselves. Interviews typically lasted for around an hour in length. Most interviews were conducted within a week or two of the previous one.

1.4.2 Field site mash up – COVID interruptus

After 5 months of in-person work at the gym, the head trainer was forced to shut down due to the COVID pandemic and accompanying stay-at-home orders. Coach and other Parkinson's boxing trainers at gyms around the world faced an ethically complicated decision. Many Fighters attend classes four or five days a week and depend on this regulated movement to maintain their health and stall disease progression. Providing a make-shift solution to keep them moving was urgent. The program's headquarters quickly put out a series of YouTube videos for scaled-down home workouts, and considering the uncertain nature of everything, those would

⁵ We sat six feet apart (outside and inside) while I wore a mask but she did not.

have to suffice for our San Diego fighters while pandemic living began to take shape. Coach had reasonable concerns about the safety of holding the class online: keeping an unstable Fighter from falling is a large part of the job and that's difficult to do virtually. According to him, his top goal at the gym is "no falls."

A month passed before it became clear that the world had moved online, and a biweekly virtual (zoom) class was adapted in April 2020. The transition was remarkable and spoke to the adaptability of the group. In the first week, there were regularly 35 individuals, which exceeded the size of the larger in-person classes. I struggled to find my place in this new setting. I did not feel right about attending classes without paying if there was no help that I could be to anyone. I dropped into the sessions before or after class "just to say hi and see everyone" and received a healthy dose of teasing about my absence during the hard work. The stubbornly humorous and light-hearted group always left me smiling. Socializing before and after class was an important component to the program, and the online format complicated the natural flow of this but allowed fighters (and me) to relive some of their better conversation topics and share tips and stories with a larger group. The loud and crowded gym had not been the easiest place to share insights with more than a couple of people at once.

I knew that the female fighters had occasionally met for pot-luck gatherings, so I set out to digitize the event on Zoom. With the help of Coach, I held an initial gathering over Zoom for the ladies of boxing to socialize. Across the board, there was a deep need for connection, affirmation, support and knowledge expressed at this meeting. I received a handful of thank you emails afterward explaining the value of casual conversation with others experiencing similar

living conditions. I decided to make it a regular event. I held 20 “ring-side chats⁶ with female fighters (one of which Coach attended as well). Fifteen of these were situated around a specific conversation theme (e.g. communicating, family relationships, confidence) though they were loosely structured and began with time for free talk. Male fighters expressed envy over our gatherings and we added a monthly “happy hour” event for all fighters to attend. I held a total of ten of these all fighter discussions. These meetings followed the same essential format as the female-only ring-side chats and were situated around a specific theme (See Appendix A for full list of conversation themes.)

Ring-side chats (both female only and all gender formats) were oriented around a topic for discussion that I generated, and punctuated by questions that I would pose to the group. Most of the thematic topics were derived from research questions and aligned issues, although two of the themes (depression/mood, and “freezing of gait” problems) were requested by a participant. These ring-side chats were enormously effective for data collection as they gave research participants the opportunity to ask each other questions and contribute to the overall shape and flow of the discussion. Not having the embodied experience to base my own questions off of, this format allowed me to learn about dynamics that I did not know to ask about (e.g. how the onset of certain symptoms felt after certain experiences, if other bilingual people switch to dominant languages unknowingly when words come faster in one than the other, the behaviors of hallucinations). They were also able to ask each other about personal life events of which I was uninformed. Following a person-centered philosophy, I appreciated the leads that were taken by participants and opted to facilitate flow over my own agenda. I took notes on follow-up questions

⁶ I affectionately termed these BLABs in my fieldnotes for Bothering Ladies About Boxing. The list of topics is featured in Appendix A.

that were inspired by comments or side remarks and reached out to those fighters at a later time when possible. For questions surrounding embodied experience and boxing, I followed an existentialist-informed hermeneutic phenomenological approach and returned “to the participants with a descriptive account of the phenomenon under investigation in order to find out to what extent the researcher’s account reflects their original experiences” (Willig and Billin 2012:121). This allowed me to clear up confusions and refine my understanding further.

We generally met every three weeks right after boxing when everyone was at a good energy level. I initially had concerns that they would be too tired after an intensive 90 minute workout and would prefer a shower and meal to Zoom socializing. I soon learned that masterfully working around energy levels was a necessity for successfully managing a disorder like Parkinson’s, in which fatigue was cited as one of the most distressing symptoms. After boxing, energy was still high, and symptoms had abated, so bodies were operating close to their best. This was well illustrated by an experience Moxie had while we were still meeting in the gym, which happened to be situated across the street from an Indian restaurant. As class ended around 12:30, there was often a scent of curry in the air that went un-noticed by the smelling-impaired fighters. One sunny afternoon, the large roll-up garage doors that covered the majority of the gym’s street-side were open, allowing the delicious scent of Indian cuisine to waft in. Moxie turned excitedly to me and said, “do you smell that?” Momentarily forgetting this particular Parkinson’s symptom, I tried to agree that it was making me hungry before realizing that was not the reason for her reaction. “Wait,” I stumbled. “Can you *usually* smell that?” Moxie began shaking her head. “I can’t usually smell *anything*! But sometimes after working out, I get some of that back for a bit.” After class, fighters have a couple of hours of heightened

energy and mental alacrity despite their tired muscles. For this reason, most events ended up being scheduled immediately following boxing class.

Participants had dates of the situated-conversations for eight months in advance (after the first four meetings) but were informed of the topic to be discussed in the e-mail invitation that I sent out a week in advance of our meetings. Coach publicized the events in class the days leading up to the events. All fighter happy hour invitations were sent through Coach who shared with me the female fighters' email addresses but did not feel comfortable turning over the entire roster. These invitations also went out a week in advance and included the topic to be discussed. On a couple of occasions, fighters were unable to make the conversation but had opinions on the topic that they wished to share and reached out to me individually with their thoughts by email or to arrange a time to meet and discuss. Conversations were not recorded or shared with the fighters who were unable to attend.

1.5 Chapter Outlines

My dissertation chapters are organized according to the journey of the Parkinson's fighter – from diagnosis, to joining the gym, to internalizing a fighter identity. In chapter two, I describe the initial phenomenological and diagnostic process that initiates the person into life with Parkinson's. I demonstrate how diagnosis is situated within the context of local understandings of disease demographics, social norms and intersubjectivity. Specifically, I analyze the gendered experience of healthcare in which women struggle to have their somatic experiences recognized as symptoms of illness, as well as the consequences of such doubt and ambiguity at the beginning of a progressive disease. I trace the trajectory from diagnosis disclosure and initial depression through a three to five year “honeymoon period” and into the remaining fight. Of continued concern is the cycle of delegitimation and (re)legitimation as new symptoms

constantly pose the question: is this Parkinson's, aging or something else? The chapter concludes with a consideration of how agency is negotiated through a series of health-oriented and relational practices that become a key component of the hidden work of everyday life with the disease.

In chapter three, I examine the lifeworld of the gym and the utility of boxing as a healing modality, applying the social science of sports to demonstrate how athletics can be used as agency-building tools by disempowered groups. I illustrate the experience of acclimating to the gym community and developing a fighter identity, then explore the motivations for joining and remaining in the group. Morality and boxing are discussed, as I follow others' arguments that far from anti-social or amoral, boxing affords a space to cultivate and perform an ethically engaged self.

In chapter four, I analyze how embodiment of ethical subjectivities is facilitated through the acquisition of a novel somatic mode of attention at the boxing gym. I use a neuroanthropological systems approach that incorporates paradigms of embodiment and grounded cognition to explore the cultivation of resilience through the guiding metaphor of "fighter." I demonstrate how the gym creates a zone of empathic resonance that offers protective benefits in the form of social bonding, culturally and personally meaningful engagement and endorphin release. This zone affords the opportunity to feel a sense of normalcy that is affected by the disease and the challenges it poses to staying in rhythm with others.

In the last chapter, I consider the effects of this work on the research participants themselves and conclude with a look into the future of the gym. I consider avenues for further research with Parkinson's Disease and discuss the limitations that were faced in this research. Ultimately, I propose that despite a later-in-life initiation for participants, boxing offers a

culturally meaningful idiom of resilience that configures the experience of self as familiar, ethical and valuable while projecting an image of moral personhood to the larger community.

Chapter 2 Diagnosis Parkinson's

Having described the basic pathologies of Parkinson's and the healing modality most commonly employed (L-Dopa replacement therapy), I turn now to the phenomenological disruption that initiates the journey to Parkinson's fighter and illustrate the lived-experience of the disease. In this chapter, I demonstrate how Parkinson's is experienced as an "Other" within the body capable of influencing behavior but distinct from the moral personhood of the individual. I will then explore the dynamics of receiving a Parkinson's diagnosis and searching for appropriate treatment through three case studies of female fighters who do not fit the profile of a typical Parkinson's patient (male). Continuing this journey, I will depict the fallout from receiving a diagnosis that includes a honeymoon period of symptom regression before intensification and the difficulties that these changes place on relationships. Of particular significance to the clinical experience is the cycle of symptom delegitimation and legitimation that is elicited by the progressive dimension of the disease. Finally, this chapter will conclude with a discussion of agency and the implications for aging with a disorder that invisibly challenges internal agentic capabilities in a culture that places a high value on self-sufficiency.

2.1 Embodied experience and the phenomenology of Parkinson's

While Parkinson's is a highly idiosyncratic disease, there is a shared "illness reality" consisting of "typical experiences, a set of words, experiences, and feelings which typically 'run together' for members of a given society" (Good 1982: 148 cf Ware 1992:347). This reality is stratified and further personalized at each stage of the disease depending on a person's unique collection of symptoms but the foundations are similar. One of the shared feelings is a sense of shrinking or sharing space with the disease. When faced with explaining his symptoms to his

young daughters, Parkinson's Advocate Andy McDowell chose a concept deeply familiar to children – being small. “My world got smaller,” he wrote in a poem, “my handwriting, my voice, my walk, my spirit, my balance, the space in the world I took up.” Andy describes how the disease crept up on him slowly until it announced its presence mercifully giving a face to the disruptor. In his early forties, Andy was diagnosed with early onset Parkinson's after two years of tremors and depression. His wife had given birth to their second child, and they realized a young family needed a unique approach to living with the disease. Developmental disorders are difficult to understand for an educated adult; explaining the implications to children sets an entirely new challenge. The McDowells turned the disease into its own family character. They named him Parky and when Andy was having a bad day, the girls understood it was Parky acting up. To the entire family, the character of Parky became a recognized Other sharing space in Andy's body.

In Byron J. Good's (1992) cross-cultural consideration of psychopathologies, he argues that the experience of illness as an Otherness within the body is a universal phenomenon. While Andy McDowell is younger than the average Parkinson's fighter, his story demonstrates the feeling of internal alterity that chronic conditions engender and the insertion of another character to family dynamics and the lifeworld. The Otherness of the disease is not bound by the body to the individual; rather, it becomes a part of that person's lifeworld, social networks and the larger ecosystem to which that person contributes. Here is where it threatens moral dynamics of personhood. As Parish observes of morality, “it is experienced in passages of intersubjectivity that register an inescapable existential challenge: how is one to respond to the existence of another person?” (2014:33). How is one to respond to the existence of an Other *within* a person?

How does one disclose this condition to their social world? One way is to give it a name like Parky and reluctantly accept it into the family.

Beyond the relational component, Parkinson's *feels* like sharing space inside the body. As one woman wrote in a published letter in the New York Times:

I had been told that reality is a construction of the mind, and I believed it, but I had never had a chance to test this theory. What I was about to discover is that chemicals in the brain - in my case, absence of dopamine - are acting as interior designers, shaping space this way and that way, shortening some distances, flattening perspectives, raising steps, adding or subtracting a couple of inches here and there to the height of chairs, steps and thresholds.

The influence of Parkinson's on the individual's phenomenologically informed subjectivity is well illustrated here. Patterns of sensorial objectification are deeply cultural (Csordas 1993, Hinton et al. 2008), and our somatic orientations change throughout our lifespan. While these changing modes of attention are gradual and consistent with external reality among typically aging adults, Parkinson's disrupts this connection, impairing the ability to make accurate spatial measurements and experience the body in place.

It is natural for an aging body to attend differently to various aspects of bodily comportment over time, continuously learning new embodied peculiarities that demand slight re-adjustments to sensibilities. These changing subjectivities provide an opportunity to acquire novel embodied orientations, even later in life. However, divergent experiences of aging may threaten one's ability to engage in regular activities and perform a moral personhood should physical capabilities be unable to meet social demands. While certain moral framings surrounding illness may provide psychological comfort by accommodating limitations, they are also capable of causing damage to the individual (Hollan 2004). This is particularly true when accommodations are not enough to fulfill cultural (or personal) expectations for adjustment and performance. Sara Lamb (2019) has demonstrated how the trope of "successful aging" has

induced anxiety for individuals who may have a decent level of subjective well-being but are incapable of measuring up to the parameters of “healthy” independence in later life required to be deemed successful.

For adults in the United States, independence, self-control, productivity and asserting personal will are frequently tied to moral experiences of aging (Becker and Kaufman 1995, Lamb 2014). This extends to internal sensorial dimensions of personhood, as many US Americans feel an unachievable imperative to control their embodied experience with enough will power. Multiple research participants expressed the moral necessity of the intention to control bodily responses in an almost confrontational manner. When I asked how one negotiates with the body when it feels resistant to exercise, one fighter said that she refuses to give this feeling a say in the matter. Another fighter articulated the importance of being “the boss” over the embodied experience (including neurological events). In his examination of morality as a theoretical framework, Jarrett Zigon observes, “to be moral is to inhabit a bodily disposition, one might even say inhabit a soul that is familiar to oneself and most others with whom one comes into contact” (2007:135). For my participants, to be moral also means to inhibit certain bodily dispositions that may interfere with healthy engagements. This presents a particular challenge for my participants who are losing control over the familiar embodied practices of the moral self that can be said to form an ethical subjectivity. By positioning the disease as an Other that is not representative of the self, the individual is granted some moral agency over the strange movements or behaviors (this notion of moral agency will be discussed further later in this chapter).

Parkinson’s fighters have found that exercise and physical activities re-shaped their experience of space within the body. As one woman shared, “I found that playing um pickle ball

and tennis and different kinds of activities can be very helpful, particularly with balance... I'm so involved in what I'm playing, in what I'm doing that *I've got my mind all to myself and that really helps.*" Fighters' descriptions reflected that there is a particular nexus of physical and cognitive activity that frees the mind and nourishes the self.

Each person with whom I spoke could tell when their body was low on dopamine and needed more. Most of them had activity monitors or smart watch alarms to stay ahead of the feeling, but everyone recognized the embodied experience of pathologically depleted dopamine: "heebie-jeebies" or a sort of embodied yet dissociated anxiety takes over the body. Participants were careful to explain that in this instance, the feeling of anxiety was not associated with any mental activity or concern; rather, it was experienced as an unsettling presence tying up the stomach and making the heart and muscles dance awkwardly around where they typically lie unnoticed. There are multiple types of anxiety that accompany Parkinson's, including more cognitively-engaged worrying. Recognizing the type of anxiety in a given moment becomes an embodied skill.

2.2 Diagnosis Stories

Learning to discern between somatosensory experiences does not guarantee that one will be trusted as a valid source of knowledge on one's own body. This struggle with legitimation was faced by many of my female participants, though when discussed in an all-fighter ring-side chat, it was surprising to many of their male cohort. In this section, I will discuss the dynamics of being diagnosed for a disease in which you are a minority of the community and the particular challenges that women faced in their clinical encounters. I will tell the stories of three female

fighters as they searched for answers and treatment to illustrate the textured experience of these encounters.

2.2.1 Gendered Dynamics of Diagnosis

Many participants say they were confident of something being wrong with their health before anybody would believe them. This was an especially prevalent experience among the women who were frequently written off as overly stressed, hormonal, menopausal, or concussed. In the current United States healthcare system, the journey to a neurological diagnosis is long and arduous but it is not equitable. As I will explore in the following section, healthcare like many structures within the United States works better for some than others resulting in a variety of diagnostic experiences. Additionally, historic notions of illness demographics have biased research studies to match the current demographics causing self-fulfilling prophecies.

Doctors do not have time to consider all potential illnesses for all bodies, so diseases appearing in an unexpected body are often misdiagnosed or disregarded entirely. Chelsey R. Carter has recently written about this phenomenon in the medical discourse on amyotrophic lateral sclerosis (ALS), which is viewed as a white person disease, leading to massive neglect of Black patients. Parkinson's is often touted as affecting men twice as often as women (Van Den Eeden, et al. 2003, Marras, et al. 2018). This leads researchers to collect and analyze at least twice as many male samples as female samples. In fact, they occasionally will go out of their way to recruit male samples, as women are more likely to volunteer on their own. What Carter has termed a "health omission" is actively occurring among women in this community, as researchers and clinicians are locked in an echo chamber of expectations. This is especially worrisome as we see the incidence of Parkinson's Disease rising globally, which is not solely

due to increasing numbers of older adults (Dorsey, et al 2018). Factors such as environmental pollutants including industrial cleaning toxins could alter the landscape of Parkinson's patients.

Responsible research must consider the people currently on the margins who may have different care needs than the current typical patient. Women are one such group. Aside from the obvious on-the-ground implications that this has on the timing for women receiving a diagnosis for a progressive condition, it has a strong impact on their treatment. Joining a majority male group creates an awkward situation for women who are not comfortable being heavily outnumbered in support groups and classes. My field site is unique in the amount of women who belong to the gym, but they are still the minority. Further, women have expressed to me a sincere disbelief in the male-biased Parkinson's statistics considering the difficulties that they faced in receiving a diagnosis. This skepticism is not generally held by the North American medical community but may carry merit according to a 2014 global meta-analysis reviewing over 750 papers, which only found a significant difference in prevalence based on sex between the ages of 50-59 (Pringsheim, et al. 2014).

Canguilhem (1989) considers how science constructs its objects of inquiry and asserts that biomedicine relies on first deciphering the normal from the pathological. He observes the importance of attending both to the biologically normal as well as the social normative in understanding the experience of disease. Perhaps Parkinsonian behaviors are seen as more female at the onset. The embodied experiences that women are able to recognize as other than their own are not taken seriously by physicians who can map their behaviors onto existing stereotypes of female patients. It thus takes a lot more suffering to prove something is wrong. The horizon for pathological consideration is further from normalcy for a female body than it is for a male. Further, as Gay Becker notes in her account of disrupted lives, "the lack of

acknowledgement of embodied distress heightens the difficulty people have in giving voice to bodily disruptions” (1997:11). Multiple female participants reported anxiety over people perceiving them as “crazy” because that is the default category for a woman who is insistent upon her reality in the face of dispute. Thus, this long and elusive process of gaining access to a neurologist – much less a movement disorder specialist – creates a mine-field for reality contestations.

2.2.2 Moxie

Moxie was one of the women who experienced a frustratingly long diagnostic process but was persistent in her quest and demanding of good treatment. She lacked the hallmark tremor but found herself losing her usual balance and strength. The daughter of a doctor, she did not believe the clinicians who suggested her experiences were due to menopause or the arthritis that runs in her family but struggled to find the appropriate specialist. After catching her heel, falling and splitting her lip open landed her in urgent care, she finally found herself in front of a doctor who took her concerns about balance and general lack of embodied familiarity seriously and wrote a referral to see a neurologist.

Moxie: I pretty much thought everyone with Parkinson’s had a tremor. So the neurologist came out... and he goes: walk here, walk there. And then he said to me, “you have Parkinson’s. Here, read these three pages of information. Here’s a prescription. Comes to me in six more months.”

Julia: Ridiculous. What were the pages? What did they say?

M: They were a poor printout of a book of a Parkinson’s entry. So I stood up, and I said, “Hell, no, you’re not getting-” I blocked the door. And he panicked. I was... I said, “sit down.” (Imitating doctor’s imaged thoughts) *My god, gonna be a crazy lady.* I said, “Okay. I am not who I am. I’m your – I’m your sister, your mother. I’m your daughter. I’m your wife. And I’ve just been told that I have this neurological disease. Where do I go for a second opinion?” Because he was a Botox specialist. I said, “I’m not leaving here until you give me a recommendation for the best.” And he was just, he was like “oh my god,” and he goes “well, there’s this new woman... Just joined UCSD. She’s running a movement disorder center. We don’t have one of those here. Maybe we can get

you in.” And I said, “I’m getting in the next 48 hours or I’m going to be back here in your face every day.”

The force of Moxie’s response surprises even herself and is a clear culmination of frustration and anxiety that has grown with every step of this diagnostic journey. She calls on the cultural trope of hysteria to justify anxiety surrounding communicating her feelings to the doctor. She fears being considered crazy and has been experiencing self-doubt over her physical experience due to her current clinical reality. She knows that receiving the designation “crazy lady” may delegitimize her experience. She is also a woman who has had a successful career in Human Resources and is experienced in perspective-taking and approaching people from a mindset that is accessible to them. By asking the doctor to remember his own family members, she has activated the part of his brain that sees her as a human being with a reasonable emotional reaction and fear over receiving a scary and unfamiliar diagnosis. Initially a little embarrassed by her intense behavioral reaction, she later overhears a new patient being referred to the movement specialist from her former neurologist and felt pride. She had been able to make a difference for future patients by calling attention to the limitations that this neurologist was unable to acknowledge within himself and his department. Now, he refers Parkinson’s patients to a movement disorder specialist, where they are likely to receive the appropriate spectrum of care beyond the pharmaceutical trial and error that he had to offer. There are many different subspecialties of neurology, and finding the right physician is an enormously unappreciated burden.

2.2.3 Blizzard

Blizzard traces the origin of her Parkinson’s to a traumatic brain injury (TBI) that she sustained in a horrific car accident that resulted in the death of her mother. Blizzard’s loss of her

mother coincided with her loss of full body ownership and marked the beginning of a long and painful path to a Parkinson's diagnosis. Blizzard felt her body slow; she lost her sense of smell; her handwriting shrunk; her arms stopped swinging while she walked. An ear, nose, and throat (ENT) doctor explained away her lack of being able to smell as an effect of the TBI. She had serious concerns about her lack of balance, but these were dismissed as a side effect of her "just being upset." It was only after bringing her husband along with her to a doctor's appointment to testify on his observations and receiving a recommendation from a friend that she pursue a referral to see a neurologist that Blizzard was able to find a clinician capable of diagnosing her (although not treating her).

Blizzard's mental instability was seen as the cause of her physical imbalance. The temptation to draw a causal inference between her grief and her embodied experience was too much for clinicians to avoid. Here was a woman who was looking for a way to explain the intense grief of losing a loved one by presenting psychosomatic feelings. The explanation of an alterity derived from the emotional experience of grief satisfies any concern of literal pathology.

Ironically, the neurologist who finally did see the Parkinson's in Blizzard did not appreciate the value of emotional and psychological support: "He was nice enough, but he didn't – you know, I said, 'Well, I wonder if I should sign up for a support group or something.' He goes, 'Oh, you're not there yet.'" Blizzard described feeling discouraged from seeking support. Her doctor's response had communicated the idea that only people who are far along in the disease will find value in a support group. Blizzard "wasn't happy with the way he handled that," so when she had the chance to change her insurance plan, she took the opportunity to find a better doctor. She shared the experience of being dissuaded from joining a support group again in a conversation with other female fighters on a Zoom call, and there was uproar among the group.

They felt that not sharing the information was unfortunately understandable, but actively discouraging that connection was downright irresponsible. There is validation in hearing the experience of disappointment is justified in resolving the self-doubt that *invariably* comes from a clinical professional devaluing one's lived-experience. Multiple women shared negative clinical encounters almost as a hazard of the gender. As caretakers, they are supposed to be the ones to take care of themselves and others. Some doctors or clinical encounters represent one more barrier to care and must be acknowledged as just that.

Both Blizzard and Moxie shared the imperative to be one's own advocate. Blizzard brought her husband into the diagnostic process when she felt that she was not being heard and she could not get through to her physicians. Moxie had the opportunity to express her dissatisfaction with her clinician and set herself up for better future care. She waited until she had received a diagnosis (and simultaneously a referral for a movement disorder specialist) before sharing the news with her husband.

2.2.4 Peregrine

Peregrine had had a similar diagnostic experience as Blizzard in that her diagnosis came with little information and 6-month follow-up appointment. She found the doctor himself to be a nice person, but she felt that his lack of effort in educating her about the disease in any way was ridiculous. Eventually, she found a new doctor, but for her, the lack of information is one of the most unsettling things about the disease.

Facing a decision to have a deep brain stimulation (DBS) device surgically implanted into her brain, she discussed her dilemma with the group of female fighters during a virtual ring-side chat. The surgery is supposed to reverse the clock about five to ten years on Parkinson's progression and decrease the amount of medication needed. This is a blessing for individuals

who are taking dozens of pills multiple times a day, but the surgery is risky. One of the male fighters who had had the surgery was left with diminished dexterity in his dominant hand (which had not been the side affected by Parkinson's), effectively disabling him from performing music in the same way. Peregrine was very ambivalent about whether or not to pursue this treatment. She was not a fan of the idea of brain surgery, but multiple medical personnel had advised her that she was a perfect candidate and at the perfect time in her disease to undergo the surgery. The idea of returning to five to ten years ago is very tempting. As she says, "those were the good years." One of the issues that is concerning her, however, is the lack of women to have had this surgery done. She cannot understand why she knows multiple men in the community but no women who have had the surgery. Granted, there are many more men in the community to begin with, but she cannot understand how there is not a single woman who can share her story. Coach pointed out the lack of women who have elected to have DBS to her upon hearing of her interest. He acts as a go-between network at times, referring different gym members to one another when they come across similar issues. He, too, was surprised and confused by the omission in his own circle.

Peregrine's experience highlights the complications of being a woman with Parkinson's exceed the gender bias of researchers and clinicians. An exclusion of communicating gender-based outcomes to women making healthcare decisions (such as whether or not to undergo invasive brain surgery) has nurtured feelings of isolation and complicated important health care choices. As mentioned, Coach acts as an intermediary at times and introduces people who could benefit from sharing their knowledge with one another. The female fighters have expressed gratitude for this and a deep sense of solidarity with one another, eager to see the right outcome for their friends. Our regular meetings on Zoom have provided a space for the women to discuss

these issues and empower one another with support and encouragement to self-advocate. I have no doubt that decision-making support groups and community building among women with Parkinson's at an institutional level could offer a tremendous benefit to people facing life-altering treatment options.

2.3 Honeymoon and Fallout

2.3.1 Initial Reaction and Depression

Upon diagnosis, most people simply receive a prescription for levodopa-carbidopa (dopamine medication) and a follow-up appointment scheduled for six months later. The patient is told that they have Parkinson's Disease and that it is a progressive, degenerative condition that will worsen with time and possibly given some fliers. Idiopathic (or not inherited) Parkinson's accounts for around 90% of cases. Because of this, many people have little to no knowledge of the condition before receiving the diagnosis. The response to being diagnosed with Parkinson's is as varied as the disease itself. For some, it is a relief – steady ground after a tumultuous storm of self-doubt, confusion, misdiagnoses and fearing the worst. “After all, at least it's not Alzheimer's or cancer” is a common sentiment expressed by fighters. Some participants discuss the experience of adjusting to the diagnosis as being filled with grief. One fighter shared: “Mine was like grief, like grieving when I was diagnosed. And then when my whole world went upside down, I had to leave my job and I couldn't do my job anymore. And that was very difficult for me. And I felt like I was kind of going through a death.” Parish (2008) discusses how grief can cause an embodied response through disrupting models of self and Other as a “relational pair.” For people who strongly identify with their career and have close connections with work peers, losing the ability to engage in a ritual process of self-actualization displaces a sense of purpose

and meaning. Many Americans have been enculturated to define themselves through their paid occupations (Good c.f. Hay 2010). This fighter had been a working, single mother who'd handled every challenge that had been thrown her way in stride. Losing her ability to continue to stride at all was experienced as a type of death: "I had to kind of bring myself out of that and realize that no, death is: I'd be dead, I'd be six feet under. I'm not dying, nobody's dying here. I just have a challenge. And I had to really have an attitude change, and deep soul searching." She had to very consciously realize that she was not planning a funeral, but the rest of her life. Another participant explained how she wouldn't even say the words "I have Parkinson's" for months, instead telling people that she "had been diagnosed with Parkinson's." Eventually, they found that the energy it takes to deny the experience is better spent elsewhere. One fighter compared this relationship to the Parkinson's Other to learning to surf a wave instead of jumping up and letting it hit you in the face.

Despite this initial stage of depression, many individuals experience up to five years of a "honeymoon period" after the initial diagnosis and beginning use of levodopa. Once levodopa treatment begins, many of the symptoms that had led them to the neurologist in the first place retreat and people have a tendency to feel like they have managed to figure out Parkinson's. Parkinson's Disease is related to both a severe lack of dopamine itself as well as improper regulation of the dopamine present. Both supplementation and temporal management of the neurotransmitter are required (Marsili, et al. 2018). The further along the disease progresses, the harder this balancing act becomes. Oftentimes, people with Parkinson's claim that the first few years offered a deceptive sense of control that had them feeling proud of their ability to handle the disease with minimal disruptions, only to have that hope dashed as the disease progressed. During this time, people who have yet to retire are likely to continue working and carrying on as

usual. Deciding whether or not to reveal this diagnosis to co-workers depends on the person and the profession.

For people who held positions of power in which they were making decisions that affected the lives of others, timing of disclosure presented a particular challenge. One Fighter, Viking, had worked in a leadership position at a Chamber of Commerce and struggled to accept the diagnosis for fear of what it would mean for his profession. The perception that others had of him and his ability to do his work without compromise was put in great jeopardy. In fact, this was a big reason that he chose to retire when he did.

Two of the female fighters shared similar stories. Moxie found the decision to leave her job excruciating and identity shattering, but it was the ultimate act of a devotion to a meaningful career and organization that she had loved. After spending decades excelling in the art of human resource management and essentially relationship counseling, Moxie found herself having to take naps in her office during the day and returning home without an ounce of energy for her family or self-care. She worried that her diagnosis would be used to undermine her careful work. Moxie talked the talk and walked the walk when it came to feminism and anti-racism. She had hired a diverse group of individuals, a majority of whom happened to be women. It's relevant to note that she was working in the nonprofit sector, which is frequently a female dominated domain. All the same, her commitment to equity had ruffled some feathers over the years, and she had had to steadily stand her ground as part of the job.

After she heard of a potential lawsuit that included a discrimination claim against her from a white male employee whom she had not promoted (instead choosing "the better candidate" who happened to be female), Moxie's anxiety surrounding her Parkinson's condition grew. She couldn't stand the idea of letting her employees and co-workers down, and she

imagined the disease being used as cause to question the integrity of her work or overturn an appropriate hiring decision. The case was thrown out as unfounded, but Moxie decided it was time to stand down all the same. Before leaving, she insisted on calling a meeting to tell the staff why she had to retire ahead of schedule. I wondered if it was to raise awareness of Parkinson's or avoid rumors developing. She explained:

I couldn't have these people think that I just walked out on them. And I didn't want them to think that it was because of the executive director. I loved her. I thought she was fantastic. I still do. And she was a great leader, but when you get in executive warfare... I'd hate to have somebody say, you know, I left for some other reason.

As difficult as the decision had been, it was “liberating” and gave her time to focus on figuring out how best to fight Parkinson's. For Moxie, like other fighters whose careers required careful communication skills or complicated executive functioning, it was painful to let go of that part of her identity, but ending the chapter on her own terms saved her from the embarrassment of watching her reputation degenerate along with her body.

2.3.2 Disclosure and relationships

As multiple anthropologists have contended, “personhood is a fundamentally relational concept” (Mauss 1979 c.f. Buch 2015b:42), and as Moxie's story demonstrates, fallout from a diagnosis like Parkinson's is not confined to the individual but reverberates throughout the family and community. For this reason, people are often careful about when and to whom they initially disclose this information. If people are already noticing a change in performance, the diagnosis can offer an explanation that is biomedically approved. Kleinman calls attention to the possible “gains” of illness that “restructure family relations and communication patterns” (Kleinman 1997:138). For people whose friends or coworkers had begun to question their recent behaviors or performance, disclosing the diagnosis offers the opportunity to explain the

awkwardness and start afresh with the new understanding that irregularities are inevitable but unintentional.

For Highlander, one of the younger fighters working in the biomedical research industry, the diagnosis inspired her company to invest more resources into their projects that targeted Parkinson's leading to some exciting and impressive gene therapy research. Working as an administrative superhero to C-level executives, her employers were unusually well-situated to be understanding of her diagnosis and what that means for her work and personal needs. They are supportive of her taking time off to go to exercise classes, doctor appointments, even my zoom group meetings throughout the day. It is rare for a corporation to be so supportive, but it is also rare for a person to be as productive and valuable a member of the team as she no doubt is. Highlander's story demonstrates the dynamic effect that the status of one brain can have on a network and the domino effects thereafter. She has already contributed a significant amount to getting the fighters back to boxing in person safely and efforts to cure Parkinson's in her first diagnosed year.

Magma, a female fighter who had retired, was able to find social capital in her condition early on. She realized that disclosing her diagnosis was a little piece of activism that she could do to fight stigma and help others receive a Parkinson's diagnosis. In effect, she stumbled into a shared "gain" that engendered an opportunity for a proximate party to "restructure family relations and communication patterns" (Kleinman 1997: 13). She hoped that her honesty with friends and family members of friends with Parkinson's would make it easier for them to uncover aspects of family relationships that may not have been re-examined or reflected upon otherwise. This was exemplified by her encounter with a casual friend. After discussing her Parkinson's symptoms, her friend heard a resemblance to her husband's recent physical issues

that led him to receive a diagnosis. Plus, if she was able to stay active in the community and still perform a healthy and authentic version of herself, she could show any other people who receive a similar diagnosis that it does not have to be a reason to withdraw. While reflecting on her disclosure experience, Magma shared, “I think keeping it a secret like that, for whatever reason you have to do that, kind of keeps people in the dark and not knowing about the disease and how prevalent it is.”

Fighters who may have underplayed their health concerns to loved ones are put in the position of delivering shocking news after receiving a diagnosis. For people who are used to occupying the role of caretaker, developing a chronic condition promises to disrupt previous relationship dynamics and expectations for the future. Complicating the issue further is the need to care for older parents. One fighter whose parents were both in poor health towards the end of their lives chose not to reveal her own condition upon diagnosis. News like that could only diminish their quality of life and they did not have many years left. She didn’t want them to spend that time worrying and praying for her. This speaks to the complexity of negotiating the introduction of new conditions to a care network.

Disclosure does not just occur once with this condition: “Biographical disruption is triggered not only by the onset of chronic disabling illness but also by any major change in the condition” (Becker 1997:123). Withholding the severity of certain cognitive or neuropsychiatric symptoms such as hallucinations has multiple motivations. As the disease progresses, individuals lose decision-making power and become an increasingly less dependable node of the network. With time, whatever level of trust that loved ones previously had in the fighter’s ability to self-regulate erodes, and privileges like driving or hiking alone become safety risks. This section has demonstrated how Parkinson’s influences the relational dynamics of the self and presents new

challenges to social terrains. Complicating this situation is the ambiguity of how the disease will ultimately progress and when different capabilities will diminish. According to participants, the pessimistic seeming medical narrative of progressive degeneration can complicate attempts to incorporate the disease into daily life. In the following section, I explore how the medical narrative and issues of legitimacy problematize the illness experience for people with Parkinson's.

2.4 The Medical Narrative

“They tell you it's only gonna get worse from here.” - Blinder

Since many individuals have little to no knowledge about Parkinson's at the time of diagnosis, the initial introduction to this disease and what they can expect from a life with it is information that requires more depth than a simple pamphlet can offer. The particularly ambiguous trajectory (including which symptoms a person will experience) can be a confusing and frightening proposition to comprehend. Many fighters feel that the way the disease is presented to the patient initially, and the emphasis that the medical community places on the progressive, degenerative and incurable aspects of the disease, have the effect of obscuring a person's remaining potential for growth. Disregarding the person's capacity for development can have harmful consequences on the health outcomes of patients. As Gay Becker observes in her work studying disruption, “how the body is represented may be a critical factor in shaping the nature of embodied distress” (1997:83). As one fighter, Blinder opined:

They tell you that it's neurodegenerative and it's progressive. That's the first thing they tell you like you really have to know that. And then you think that so you neuro-degenerate and it's progressive. But if you think it's not and you try to keep going and go to Rock Steady every day, you find out that it's not as progressive as you thought it was.

Blinder voices the frustration of feeling that even the people who are supposed to be in your corner and able to help you are seemingly encouraging defeat. People hear that it is degenerative without a cure in sight, so they don't realize that they still have some agency in the course of the disease. Despite the fact that the speed and progression of Parkinson's Disease can be influenced by the proactive behaviors of the individual, many people are left to believe that their trajectories have been set. Luckily, the Parkinson's community is vibrant and works to fill in the gaps in resources that many individuals encounter and promote community outreach and exercise classes.

For individuals lucky enough to be diagnosed by a movement disorder specialist or referred to one, an entire clinical team is brought on to consult on the best treatment for the patient. This includes the neurologist, a nurse practitioner, a physical therapist, a social worker, and if/when needed, a speech therapist, occupational therapist, neurosurgeon and others. I found it startling to hear the variety of diagnosis stories and how significant insurance and luck of scheduling was to the fallout and eventual management of the disease. While one person is met with a team of specialists and support staff who are ready and motivated to help with constant adjustments necessary to accommodate the changes brought about by Parkinson's, another person is given a few pieces of paper and left to contextualize this unfamiliar condition into their lives without a whisper more of clinical guidance.

I have yet to meet a fighter at the gym who would allow any anxiety, power dynamics or medical reverence to interrupt self-advocacy efforts. Each of my participants who had a negative experience with the doctor who diagnosed them found another doctor to see. In our conversations, if ever someone expressed concerns about their doctor's treatment, the other ladies were quick to encourage pursuing a second opinion. One of the many frustrating aspects of

dealing with Parkinson's is the current dearth of information that after more than 100 years is still missing. It is not just a lack of knowledge, but changing knowledge that complicates the doctor-patient relationship. Even when a doctor is dependable, erudite and gifted with explaining new evidence, trusting this knowledge can be difficult when it is replacing a belief (or assumption) held throughout their previous illness experience. Information begins to feel like a placeholder for the next realization leading to a blameless frustration with the medical system's limits.

One issue that repeatedly arose during my fieldwork was the safe use of levodopa medication. For decades, it has been reported that taking high doses of levodopa would lead to dyskinesia - abnormal, involuntary movements (Fahn 2000).⁷ Some formulation of levodopa-carbidopa is prescribed to each person with Parkinson's to increase dopamine production, along with other medications that "smooth" and help regulate the activity of the molecule (Taddei, et al. 2017). As the disease progresses, more medication is needed (because of the degenerating dopaminergic system, and not the build-up of a drug tolerance), and doses must be increased (Williams-Gray and Worth 2016). According to fighters, pills are taken at the same time each day, but additional pills are occasionally needed in between doses, particularly while trying to find the most effective intervention strategy. Multiple participants reported that they avoid taking any more dopamine than absolutely necessary out of fear that their bodies will develop a tolerance to the medication, or drug-induced dyskinesia. Newer guidance urges people to take as much medication as is needed to control their symptoms, and counsels patients that this will not result in developing dyskinesia (Litvan 2021). For many people with Parkinson's, the doubt

⁷ The actual mechanisms behind "levodopa-induced dyskinesia" (LID) are dynamic, complicated, and still under research (Hansen, et al. 2022).

lingers. Magma was looking for re-assurance, and asked me if I had any information on the dynamic. She said that her doctor had explained away her concerns at one point, but the pervasive anxiety within the community continued to unsettle her confidence:

I have a girlfriend who has Parkinson's and she goes: "You take too many of those pills, you get dyskinesia and dyskinesia is forever. You never get rid of it." So she has, she has me really scared. And then I talked to my doctor about that. And he said, "No. No, that's not the way it works."

Despite doctor assurances, people feel an embodied uncertainty when making the decision to take another pill and sometimes choose to suffer the symptoms instead of risking the increased dopamine intake. This is one more way that the ambiguity surrounding Parkinson's knowledge influences the daily lives and clinical relationships of individuals. Having considered legitimacy of medical knowledge, and how this influences illness experience, I will now turn to issues of patient legitimacy.

2.4.1 Delegitimation- Relegitimation Cycles

Arthur Kleinman (1997) discusses the issue of delegitimation among chronic pain sufferers who struggle to receive a diagnosis or be taken seriously by the medical narrative. Through objectifying their internal subjective experience in medical diagnostic terminology, he demonstrates the possibility of "relegitimation" in which individuals are able to understand symptoms of their illness as "emblems of a new way of engaging in the stream of experience" (Kleinman 1997:140). For Parkinson's, not only does legitimation carry personal significance, but it activates embodied capital in the form of focused and purposeful attention to certain bodily processes. As the disease progresses and new physical experiences are added to the mix, this process of delegitimation and relegitimation occurs repeatedly. The lack of a distinct and straightforward symptom profile complicates the process of legitimation.

A frequent complaint made by fighters is the ultimate lack of clinical knowledge of the disease and uncertainty regarding their embodied experiences. People accept that as knowledge about the disease grows, doctors learn more and change their recommendations and guidelines, but this does not fully appease the frustration of repeated expectation shattering. This, along with the embodied experience of knowing more than the doctor about the disease leads to frustration but acknowledgement of the limitations. Frequent sentiments shared by fighters included: ‘Doctors don’t know what they’re talking about,’ ‘They’re still trying to figure this thing out, they don’t understand what they’re seeing’ and, ‘They’re just guessing.’

For the women, this feels like an extension of the gendered sensorial delegitimation that complicated their diagnosis in the first place. Initially, illness experience is delegitimized as somatic symptoms were written off as byproducts of hormones or stress, an almost self-inflicted wound or hystericizing of mundane sensations. Now, it seems that everything is “thrown in the Parkinson’s bucket.” That said, there is also frustration when causal lines seem evident to the fighter but are dismissed by the doctor.

The continuous nature of this legitimacy cycle can be so exhausting that one fighter instituted a “Three Day Rule” for new somatic symptoms. Now, she waits three days before beginning to worry, wonder, or think too much about a strange feeling in her body. A simple tweaked muscle or sore joint does not necessarily feel like it had earlier in life. After the death of her mother, Moxie faced some challenging family dramas that resulted in ruptured sibling relationships and an abundance of work clearing out their mother’s home. During this time, she began to experience dystonia, an involuntary and prolonged contraction of muscles that is incredibly painful. Moxie, who prides herself on her high pain tolerance and toughness under physical (and mental) stress, found herself writhing on the floor in pain and literally turning

black and blue from the bruises these contractions were causing. This was relatively early in my fieldwork, and I remember discussing dystonia with her at the gym. She was fervently searching for something to ease the pain, though at the time I was unaware of the family dynamics and loss that she was experiencing. Hearing her description of the pain and bruising later left me speechless. How could this have been the same body that I saw athletically bouncing around and jabbing in the ring? The most recurrent theme in my research was this intense disconnect between internal lived-experience and externally perceived evaluations.

After a few months, the dystonia subsided and Moxie scratched it off her list of symptoms, figuratively speaking. Now she warns the others not to be fatalistic in their reactions to new symptoms. They may be temporary. Significantly, this is not a process of denial, rather a recognition of the tenuous relationship between the many nested systems within which a person is operating. In fact, this may be a valuable protective factor against progression of the disease. While accepting your condition is vital, fully internalizing every possible symptom is fatal. Allowing for the vicissitudes of lived illness experience, without becoming overly concerned with possible emergent symptoms may encourage a return to homeostasis, as opposed to a more permanent embodiment of these additional symptoms. Occasional bouts of liminality are like boxing matches: the fighter may lose multiple rounds but it's their ability to keep going that cements their status as a contender.

2.5 Agency

When I started this research, I was struck by the depiction of Parkinson's as a disability of agency in the neuropsychiatric research. As an anthropologist, the majority of my previous experiences with agency considered an outside-in approach to the ability of an individual to

effect change and act on their own decisions (de Lopez 2019, Edu 2018). “Moral agency” has taken a more microcosmic look at individuals whose behaviors, decisions, or psychopathologies have led to an exclusion from the “local ways that people come to be recognized as “good” in their everyday lives” (Myers 2015:loc 285). While this accounts for agency on the level of individual mental processes, it still describes an obstruction that comes from the community that will not accept their participation. With Parkinson’s, the neurological sub-systems critical for agentic processes are compromised by the disease (McNamara 2011). While medical anthropologists have demonstrated how “sickness presents a fundamental challenge to agency and, thus, to one’s value in the world” (Hay 2010:260), I wondered about the added difficulty of adjusting to a progressive disease that according to neuropsychiatric literature literally attacks the cognitive processes used for agentic behaviors. I also questioned how well the neuropsychiatric assessments based on imaging data and empirical measurements accurately reflected the lived-experience of my research participants with Parkinson’s.

Psychological anthropologists have documented instances of moral agency being stripped from individuals with mood disorders and other socially disruptive pathologies, leaving individuals unable “to aspire to a “good life” in a way that leads to intimate connections to others” (Myers 2015: loc298). Institutions and guardians prevent individuals who have been deemed “untrustworthy” due to a psychopathology from exercising their moral decision-making skills and engaging in the “right” behavior on their own. Being kept to strict schedules, driven to different meetings and groups and given particular medications and diets keeps individuals practicing healthy behaviors that may improve their overall physical health. However, these imposed structures can have negative effects on their overall subjective well-being and damage their individual abilities to develop a meaningful and personal engagement with the world.

Recovery-oriented mental health organizations in the United States have recognized this need for moral agency as foundational to their philosophies of care (Myers 2015). As Mageo and Knauff observe, “forms of agency are intimately bound-up with the human capacity to innovate upon if not to reimagine existing schemata; these innovations are integral to the activity of self-making” (2002:8). Blocking an individual’s agency in self-care is detrimental to efforts at self-making and ultimately developing healthy and prosocial coping mechanisms.

People with Parkinson’s face very different barriers to moral agency than many of the marginalized groups ethnographically studied in research on moral agency, such as individuals dealing with schizophrenia, addiction, psychosis (Myers 2016, Hansen 2019) and homelessness (Carpenter-Song 2019). Initially, there are very few (if any) structural limitations to performing moral behaviors for people with Parkinson’s, as caretakers and family have yet to develop significant concerns about their current ability to engage in appropriate judgment, behavior and decision-making. These expectations may create a challenging dynamic for some in which the individual is invisibly wrestling with an internal foe for agentic control and must explicitly articulate their limitations for all parties to be aware. In fact, Parkinson’s fighters, their friends and at least one physician commented on the fact that for a significant amount of the illness experience, individuals are *over-attributed* agency and communicative intent. As I heard from multiple members of the Parkinson’s community and as illustrated in the stories to follow, people have a tendency to believe that the strange movements or actions caused by Parkinson’s are intentional attempts at nonverbal communication. As Heidegger observed, “A person is in any case given as a performer of intentional acts which are bound together by the unity of a meaning” (1962 [1927]:73). Throughout social sciences, there is a general expectation that a person’s actions are intentionally communicating a deeper meaning. This is essentially Grice’s

maxims of conversation: a person communicates the amount of relevant information needed in the appropriate manner (Grice 1975:45). This is not always the case for people with certain motor and neurological disorders like Parkinson's, whose extraneous gestures are facts of physics and not intentional communication.

Perhaps due to the slow onset and largely invisible nature of the disease, it can be difficult for family members and friends to fully determine what is reasonable to expect from a person in everyday life as symptoms progress. This can lead to the over-attribution of agency and assumption of intentionality (or more morally questionable reasons for impairment, such as inebriation) creating frustration for all parties if not an embarrassing confrontation. Four separate male participants had all been denied service from a bartender who believed that they were sloppy drunk when trying to buy their first drink. Their lack of balance and rigid muscles of Parkinson's produce a stumbling and swaying that can easily be misread as inebriation, especially by people who are more familiar with drunks than neurology patients. In fact, a large reason that Dukes chose to retire from his position at a baseball stadium was the frequent misinterpretation of his masked facial expression (a Parkinson's symptom) for irritation or dismay. For Dukes, as for many people with Parkinson's (Friedman 2017), he was not aware of the impression that he was giving. To him, he was smiling and engaging in a jovial intersubjective space. It was not until surrounding expressions grew concerned when looking his way and someone inevitably asked if he was upset that his assumption of accurate mind-reading was contested by the altered mood brought about by the Parkinson's symptom. Part of his job was ensuring that important guests had a good time at the ballpark, and the disease had stripped him of the necessarily nonverbal confirmation cues that keep the intersubjective mood afloat.

Symptom attribution has a significant influence on both the individual's lived-experience and the social systems in which they are embedded: "Attributions of the cause of symptoms or problems to self or other – in concert with attributions of control – influence the conservative cognitive processes that maintain the coherence and consistency of belief systems and reinstate free choice and self-control when they are threatened" (Kirmayer, et al. 1994:585). Accepting compromised bodily control is a common struggle not only for caretakers and family members who must decipher the meanings behind strange movements, facial expressions and vocal affect but for the fighters themselves who must incorporate this new physicality into an existing self-concept.

Each fighter begins their journey at the gym with an assessment to determine their particular physical abilities and needs. It is less about being healthy enough to train and more about learning about the fighter's specific symptoms and experiences. According to Coach, the most important lesson taught at the Rock Steady Boxing training program is the oft-adapted adage: "Once you've met one person with Parkinson's, you've met one person with Parkinson's." These initial meetings provide an opportunity for the Coach to get to know each person's specific expectations, concerns, interests and problem areas. While I did not attend these assessments personally, Coach shared his observations about the reticence people have to admit that their falls and awkward physical movements were caused by Parkinson's, instead preferring to take the blame themselves:

During the assessments, I find what's interesting, oftentimes, the wives or spouses are there. And I'll say, "have you had a fall in the last six months?" And a lot of times, they'll say, "well, yes, but it wasn't Parkinson's-related. It was, you know, there was a curb and he didn't see the curb." I noticed there's a lot of denial about well, maybe the Parkinson's did actually cause the fall.

In the past, it may have been more likely for the person to regain control after tripping over an unseen curb before instead of falling fully, but with Parkinson's these moments of imbalance are hard to redirect. Coming to terms with a loved one's diagnosis can be as challenging (or more) than accepting one's own condition. With a progressive, ever-changing disease that attacks each partner's ability to find empathic resonance, the terms of illness can be difficult to read, much less accept.

Clinical evidence suggests that self-awareness of motor movements is impaired among certain people with Parkinson's (Amanzio, et al. 2010; Maier, et al 2012; Pietracupa, et al 2013). This connection has been most strongly demonstrated in regards to uncontrolled movements brought about by heightened dopamine activity from medication (Sitek, et al 2011). Likely though, there is a strong cultural and psychological element to acknowledging that one cannot control one's own body with the same mastery as in years passed. As Hollan reminds us, self-awareness is a "social product," as the self is shaped in large part through impressions of relationality and social expectations (2014:176). After a lifetime of fulfilling embodied expectations, a familiar excuse such as clumsiness heightened by stress or fatigue is less of a violation of self than sharing control with Parkinson's would be.

As the disease progresses, systemic structures begin to impinge on a person's agentic potential as a matter of public health and safety. For example, the loss of a driver's license can be devastating for some. Individuals struggle with the decision to turn over their driver's license, and people may downplay certain symptoms of experiences that could hasten a relative or doctor to initiate the driving safety conversation. Causing harm while driving to oneself or others would be highly unethical to this cultural group; however, and some feel a gnawing impetus to have their skills tested even if this leads to the end of their driving career. Individuals must find the

balance between aligning with morals of independence symbolized through driving and morals of public health and safety symbolized by turning over one's license. For all of my research participants, this included some level of on-going dialogue with friends, family members and doctors throughout the disease. The topic of driving came up in multiple group conversations. One fighter discussed his decision to have his driving abilities assessed with the group and encouraged others to do the same. Another fighter shared the pain of finally having his dream car only to wind up watching his wife drive it as he sits in the passenger seat.

Recognizing the potential danger involved in driving and choosing to retire one's own driver's license is an act of moral agency that acknowledges the importance of public health and safety. This ethos was particularly salient within cultural discourse at the time of my research. With COVID-19 decimating populations and a heated political debate surrounding efforts to slow the spread of this virus through social distancing and wearing masks in public, the moral value of self-sacrifice for the sake of public health was exceptionally high among my participants.

After spending a few months at the gym, I began to think more on one of my initial questions: if this *was* a disease of agency like the neuropsychiatrists contend, was it actually experienced as such? Or were people able to find ways of exercising their agentic self through different techniques as it looked to my naïve outsider eyes? I decided to bring up the question of agency point blank during a conversation with a group of the women and explained my meaning of the term to be "the capacity to make decisions and future plans and act on them in real time". There was a thoughtful pause, as I bit my tongue to keep from over-explaining or leading them more than I may have already, then some slow nods of recognition. Multiple women recalled how they used to be great at multitasking and being able to "just do it" (in reference to a task or

action), but now they get caught up in the moment before the activity. Although I had seen these women make plans and carry them out successfully multiple times, it became clear that dynamics of agency were complex and malleable. There are also aspects of life that feel simple yet affirming, and the loss of these subtle agentic performances were incorporated in the ethical subjectivity. As one fighter shared, “I can't do that very simple act of- and I still can't, of signing my name to a tip on a check.” Fighters discussed “the domino effect” that would occur when asked to perform a challenging task (such as signing their names).

The gym is diverse, with some fighters who are not very far along in disease progression or less impaired by it and able to offer their capabilities to the group, while others who are more affected by the disease offer their knowledge, experiential wisdom and inspiration, quite like a microcosm of an eldertopia. The clearest evidence of this occurred at the first female fighter gathering that I attended. One of the women in a later stage of the disease was driven to the potluck by her husband, who planned to return upon her call. As people began to divvy up leftover treats and leave, she realized that she could not remember the password to open her phone or her husband's mobile phone number. While this was embarrassing for her, the women were quick to compassionately step into action. The hostess was able to get ahold of Coach who had the husband's number, but it was a clear example of the disease influencing agency disrupting her ability to go home. There is also an important subjective element to making plans and carrying them out. What may look like a perfectly planned execution to an outsider may not match or include all of the intentions of the planner. Requiring additional assistance and resources to accomplish tasks that previously took minimal effort may not feel like the agentic victory that I had imagined.

Agency is negotiated through a series of health-oriented and relational practices that become a key component of the hidden work of everyday life that (like everything with this disease) becomes increasingly complicated over time. Activities and medications are carefully planned out through the day to ensure appropriate energy levels and functioning. For much of the disease, fighters develop a confidence in their routine and knowledge that their medications will quickly work to alleviate symptoms. There is a distinct phenomenology associated with the feeling of low and poorly regulated dopamine likened to the “heebee jeebees” or an internal tremor that the fighters all recognized. Most of them have alarms on their phones or smartwatches that alert them to medication times, but many say that their bodies can feel it without the reminder. After sometimes painstaking efforts involved in finding the right formulation of medication(s), successful management requires trust that the medication will restore levels of functionality and relieve the heebee jeebees once it takes effect. As the disease progresses, more medication is needed to manage the symptoms, and fighters find themselves experiencing increasing amounts of “off time” – the period in between doses when medication is not yet working. These are times in which the individual has little control over their symptoms. With attention, the frequency and severity of these times can be managed with additional medication; however, fighters often find themselves waking with lower levels of functioning.

2.5.1 Gendered Agency with Parkinson’s

Women face added visibility challenges within the Parkinson’s community in the United States. With a majority of the diagnosed population being male, women find themselves outnumbered in many settings. Even after receiving a diagnosis, a woman may be blamed for the length of time it took to receive one. The New York Times published an email exchange that illustrates this case perfectly. It is between two long-time friends (one male and one female),

who compare their experiences with Parkinson's (Heller and Vienne 2021). After a paragraph describing stumped specialists and a misdiagnosis that eventually lands the writer in a neurologist's office, she receives a diagnosis of Parkinson's Disease. She ends her email by posing a deep concern to her friend: "The question is: Why did it take so long for me to book an appointment with the right specialist? Was I mentally impaired as well as physically handicapped? What do you think?" Her friend replies with the opinion: "I think you were in denial that something could be terribly wrong. We don't want to know what we don't already know." While there is truth to the observation that as humans, we fear the unknown and health anxiety is a large part of that, I was shocked to read this assessment after the extensive amount of time that she had spent seeing each specialist to whom she had been referred. She invites this opinion with her own self-doubt and suggestion that something may be wrong with her mental capabilities considering the length of time it took to properly communicate with a physician; however, she also presents an opportunity to be reminded of the hard work she had put in to discovering the origin of her symptoms and the tremendous difficulty of finding the right physician. She searches for legitimization, even after the condition has technically offered it. Her friend follows the patient-blaming lead, and she is left to believe that she was somehow postponing this revelation intentionally (Heller and Vienne 2021).

Consulting with a neurologist is not as simple as picking up the phone and calling an insurance-approved doctor. My female research participants tended to have a more complicated and drawn-out diagnostic journey than their male peers, whom doctors are two times more likely to expect to have Parkinson's and thus quicker to spot the symptoms. Accepting the blame for a delay in diagnosis has a double-edged quality: on the one hand, it places one's moral and motivational self into doubt; on the other hand, it claims control over the ultimate trajectory of

one's experience. For some, feelings of self-sabotage may be preferable to those of victim. None of the women I talked with blamed themselves for delayed diagnoses. Rather, there was a recognition that women were generally overlooked and underserved within the Parkinson's population and a belief that this constituted a level of mistreatment. Feelings of victimization, however, were mediated by the recognition and anger at the larger health inequities existing within the United States. "You shouldn't have to worry about being able to be seen and be treated. It's terrible," voiced Ferocious during an online ring-side chat with the ladies. After Can-Do told the group about a surgery that she had scheduled to fix her teary eye, Moxie pointed out how fortunate they all were to have the healthcare that allowed them to "explore" different medical interventions. The conversation turned to the many people around the world who did not have access to such care before focusing on the other Americans who struggle "to be seen and be treated" or even able to afford their medication. Blizzard said, "It's more than sad, it's criminal." Magma agreed, "it's unethical." Blizzard summed up what we all seemed to be feeling, "it shouldn't be that way in America... a lot of things shouldn't be this way in America."

The conversation was coming off of a month filled with social uprisings and the Black Lives Matter movement had been center stage in the media. Donald Trump was the President of the United States, and his administration had created a tense political atmosphere that resulted in immigrants being detained in cages and children separated from their families at the southern border with Mexico. This upset many of the Fighters. We were also still in the middle of the COVID-19 pandemic, and a vaccine had yet to be developed. Tensions were high; health inequities and social justice were hard-to-escape topics and on people's minds. While the fighters came from diverse backgrounds ethnically, religiously, occupationally and geographically, they were all well-educated individuals with left-leaning political views, and many had a history of

activism and political engagement. These have been topics of concern before. Participating in a march or protest as a person with Parkinson's would be overwhelming and dangerous under normal conditions, but add a highly contagious virus and the risks increase exponentially. For some, it was disappointing to reflect on losing that avenue for political agency. Many of the fighters found other ways of acting on their beliefs. Charitable donations and economic support mitigated some feelings of exclusion but did not provide the same embodied connection that certain types of activism and volunteering pursuits did. It was also fairly common to participate in clinical research and Parkinson's advocacy, such as community events, fundraising walks and even writing blog posts and books. Within the first few months of the pandemic, one of the female fighters wrote and self-published a book about the use of essential oils in Parkinson's care to distribute free of cost. This same fighter also ran a Facebook group for people with Parkinson's to share information and support. Another fighter found an opportunity helping assess students' language skills remotely for a school district that had many English learning students.

2.6 Conclusion

This chapter considers the complicated trajectory of an embodied acknowledgement that something is wrong to receiving a Parkinson's diagnosis to adapting to life with the disease. The phenomenology of Parkinson's is idiosyncratic but shares certain characteristics. As the disease occupies the role of an Other within the body, spatial dimensions of self are compressed, and fighters feel a sense of "sharing space." Despite this sense of disruption, the experience of being diagnosed with Parkinson's disease can be problematized by a lack of testimonial legitimacy of women's embodied knowledge. Following the diagnosis, ambiguity of expectations for the lived-

experience of the disease creates tension for individuals as they make healthcare decisions.

Fighters optimize their experiences of agency by acting on their ethical beliefs in new ways, such as through volunteer work, supporting public health measures and acquiring new healthcare practices. Fighters recognize their health as situated within a wider historical and geopolitical terrain that guarantees them few liberties. At the same time, they are aware of the privileges that they have in regards to socioeconomic stability, social support and health guidance.

In the next chapter, I will explore how the world of the gym cultivates a Parkinson's fighters' identity and the value of athletic skill acquisition to technologies of self and health aging. I will demonstrate how boxing acts as an idiom of resilience with both intrapersonal and interpersonal benefits that provides a missing sense of normalcy and belonging to fighters who are struggling to recalibrate their sense of self, personhood and sociality.

Chapter 3 Into the boxing gym

Me? We. - Muhammad Ali (quote painted on one of the gym walls)

I arrived at the gym a few minutes early. The neighborhood is gentrifying and constantly under construction, making parking spaces difficult to secure. A typical sunny day in Southern California allows the garage doors that make up the storefront of the gym to be rolled open, creating an open and airy feel. The building is slightly elevated with a wheelchair ramp along the side of the storefront that offers a nice separation from the sidewalk and busy street. There is a block of small lockers by the front door, a mini-fridge displaying purchasable cans of water with a comically threatening name and a front desk that subtly demarcates the front waiting/business space from the world of physical training beyond. It is not a very large space, so everything is laid out with intention.

The fighters are typically punctual, and many arrive early to volley a plastic ball around a circle while they wait for class to begin. I slide my bag into a locker and take it all in. Coach waves hello and heads over to introduce me to a woman sitting at one of the two long benches positioned in front of the garage doors: 'This is Ham's daughter,' He says. 'We call her and her sister Cheese.' Each person is given a boxing nickname which creates a sense of belonging and encourages a fighter identity. All fighters, trainers and volunteers receive a name, and the practice extends to involved family members and caretakers. I introduce myself to Cheese, briefly explain my presence at the gym and ask how she feels about sharing a name with her sister. 'I think it's adorable,' she replies. 'We kind of look alike and we take turns bringing him to the gym, so I don't mind. It's just an honor to be named.' Cheese tells me her real name and shares her favorite Parkinson's term. 'They call themselves sharks,' she smiles. 'I love that.'

Like many of the caretakers (and loved ones of people with Parkinson's) with whom I've spoken, Cheese does not need much prompting to share her impressions of the disease or the gym. At first, she had been surprised by how far along in the illness some of the fighters were. She tells me that Ham attends support groups for people with Parkinson's, and those typically have fewer individuals in the advanced stages participating than she sees at the gym. This juxtaposition between intense exercise and mobility-challenged bodies had been initially unsettling to her, but the effect that the class has on her father's mood is undeniable. 'The class really tires him out but his mood stays lifted all day,' she explains. 'There are good days and bad days, but at least I know that when we come to the gym, it's usually a good day.'

I hear the Coach call everyone over to begin class. I thank Cheese for sharing her thoughts and head over to join the group of about 25 fighters ready to work out. With the exception of boxing gloves at certain stations, the dress code dictates wearing whatever supports mobility and safety. For example, many people with Parkinson's struggle with cramping feet and need to find a specific shoe type that works best for them; sometimes this means no shoes at all. Sandals, socks, sneakers, anything that keeps the muscles from cramping are fair game in this gym. It was the diverse footwear that initially struck me as out of place, more so than the collective age of the group. I didn't make the connection at first and sheepishly asked the Coach about the strange shoe situation that I was seeing.

Each class begins with a warm-up, taking big steps around the gym in a single-file line while adding moves such as wide claps for a few loops before gathering in a large circle on "the turf" for a check-in. Coach poses a "get to know you" question, such as "what fictional character do you most relate to?" or "what was the best gift you've ever received?" and tosses a medium-sized plastic ball to one of the Fighters. The boxer shares their full name, then their boxing name

and answers the question before tossing the ball to someone else in the circle. This is a trickier task than it might seem. One study found that people with Parkinson's struggled to recall as many autobiographical memories in a timed trial as the peer control group (McNamara 2011: 102). Every activity in the class is carefully orchestrated to exercise skills impacted by the disease. After the check-in, Coach goes over the boxing sequence for the day. The class is divided into four stations with different work-outs. Fighters move through these stations in small groups for five minute segments divided into 90-second intervals, with four intervals at each station. While there are dry erase boards at the stations with keywords, it is a lot to remember for the Parkinson's fighters. Having volunteers at different stations helps ensure that fighters are working out accurately and safely. One of the stations is inside the boxing ring, and this is where the boxing sequence is practiced. Coach and one of his staff (or boxing trained volunteers) typically work this station and spar with the fighters. This is where they practice the boxing sequence taught at the beginning of the class.

Today is a Friday. I'm told that there's a special tradition for the end of class on Fridays, and I see the fighters begin to perk up after an exhausting training session. Challenger encourages me to stand up on the edge of the ring so I'm out of the way but can still see. Suddenly, "Gonna Fly Now (Theme from Rocky)" begins to play throughout the gym. Coach calls for everyone to line up and positions himself behind a large heavy bag to hold it steady. One by one each boxer jogs and gives the bag ten of their best punches. The entire gym counts out the punches loudly until 10 is reached and the fighters cheer. For some, the 10 count is a little less accurate than for others because the point is empowerment, not assessment. The last fighter doles out their punches and we all return to the turf.

The class ends with its regular cheer. The group gathers into a circle with fists in the center and the coach begins the call and response. “On three! What do we beat?” The fighters should back, “Parkinson’s!” There may be anywhere between zero and four volunteers at a given class, but the fighters are always thankful. Fist bumps and congratulations spread throughout the gym. Volunteers bring the gym into the community in a way that staff alone cannot accomplish. The gym is a small business and does not have administrators or extra staff on hand. Volunteers include students, family, and friends, even co-workers. This means that nobody is there just for a paycheck.

This chapter brings the dissertation into the world and culture of the gym.⁸ I will provide a brief review of the social science of sports and how athletic enterprises intersect with socio-political positionality and hopeful futures. From there, I will explore the history of boxing in the United States, and the relationship between boxing and Parkinson’s, to demonstrate how the image and morality of boxing has changed over time. After illustrating the benefits that fighters derive from their work with the gym, I will consider their motivation for continued engagement and depict the community that develops around Parkinson’s boxing. Finally, I will propose that more than a healing modality to delay Parkinson’s, boxing operates as an idiom of resilience that benefits subjective well-being and impressions of ethical aging. Parallels between culturally-dominant values in the US and boxing culture make this practice particularly relevant to cultivating ethical subjectivities of healthy aging.

⁸ When referring to “the gym,” I am specifically discussing Coach’s boxing gym and the community of Parkinson’s fighters that call it home.

3.1 Social Science of Sport

Entire subfields in disciplines such as sociology and psychology are devoted to studying the social production and experience of sports. While a comprehensive review of these inquiries is beyond the scope of this dissertation, it is worth situating the boxing gym within a broader theoretical discourse of sports as a site for “communities of practice” (Downey 2014:113) and “the future orientation of hope [and] moral imperative for action” (Guinness 2018:314). This discourse is also highly gendered, however, and athletic practices are a political landscape not unaffected by socio-cultural norms and expectations.

Anthropological research has documented various manners in which sports engagement and athletic commerce express socio-economic, cultural and gendered tensions. “Crises in masculinity” and tensions from fiscal precarity throughout the “Global South” are confronted through sports as a potential avenue for engaging in a productive role in the world economy (Besnier et al. 2018). I do not wish to conflate the two movements, but it is interesting to note the similar masculine guarding of serious athletic pursuits that occurred in the late 19th and early 20th Century United States and United Kingdom (Van Ingen 2013). In contemporary trends worldwide, groups with fewer socio-economic advantages hope for a family member to gain “sports mobility” – indicating both the acquisition of social status and fiscally favorable geographic migration (Narotzky and Besnier 2014, Peters 2016, Guinness 2018). Despite the low likelihood of success, young men with too much time and too few opportunities devote their efforts to demonstrating potential value (Guinness 2018). Cultivating potentiality is a moral act, as seen for my research participants.

Although women have competed in the Olympic games since 1900, they were largely kept to a handful of events such as figure skating and golf (Besnier et al 2018). It was not until

the late 1970s that the US woman was given a place in the arena, so to speak. Political regulations like Title IX of the Education Amendments of 1972 (Title IX) and Amateur Sports Act of 1978 (federal anti-discrimination laws in the United States) led to an influx of female athletes at all levels (Lopiano 2000). Even still, gendered stereotypes of masculinity and the notion that empowered female bodies are deviant or otherwise liminal persist (Paradis 2012, 2014). Dupuis-Déri (2012) argues that the crisis of masculinity is an antifeminist exaggeration, as there are far more culturally appropriate male models than female models represented in the media. While this is certainly variable throughout the world, international sports governing bodies that have made efforts at “regulating fair play” with problematic practices like gender verification (Elsas et al. 2000) continue to reproduce a male-dominated ideal within the field: “Regulations have supported beliefs that female masculinity is an aesthetic marker of bodies unfairly enhanced, either by steroids or biology” (Henne 2016:6). Once again, we see familiar claims that a naturally athletic body is a male body.⁹ “Athletic” and “(physically) tough” are not morally acceptable or even recognized ways of being biologically female in much of the world.

McCaughey notes that athletic feminism challenges “the inevitability of men’s violence and women’s victimization” (1997:178). Women who engage in athletics and occupations that require a “manly” body continuously undermine an assumption of naturally gendered behavior. Boxing is not just about social mobility but adds a moral valence to aggression and demands to be respected as an energetic force that disproves the inevitability of victimization. Likewise, my Parkinson’s fighters are challenging the inevitable progression of destruction through the

⁹ In fact, research with female athletes shows that the decline in female muscle mass seen after puberty is likely due to socialization as opposed to being a natural process (though there is still a “leveling out” while males tend to see an increase in muscle mass) (Whipp and Ward, 1992).

generation of embodied capital. Many of the female fighters are self-proclaimed feminists, but boxing and physical engagement is less about making a statement about their gender than it is about staking a claim to their biographical narrative as will be explored further on in this chapter.

3.1.1 (Gendered) history of boxing

Boxing has gained a reputation for being the *manly art*, “a true ‘blood sport’ in ways that few if any other athletic activities are, as reflected in the hypermasculine ethos that underpins it” (Wacquant 1995:496). This notion has been carefully constructed and reinforced by generations of boxing historians and journalists who sought refuge for masculinity towards the end of the 19th Century (Van Ingen 2013, Gems and Pfister 2014). Women participated in bare-knuckle boxing matches at least as far back as the 1720s in the United Kingdom (Owton 2015:223). In fact, in 18th Century England, it was female boxer Elizabeth Wilkinson¹⁰ whose popularity and reputation stood above the rest: “While many women fought topless in order to titillate, Wilkinson and her opponents fought fully clothed, indicating they were serious athletes rather than prostitutes” (Thrasher 2013:59). These were not staged side fights, and this era saw particularly gruesome bouts.

In early 20th Century United States, boxing had a boost of mainstream interest, and women were encouraged to train as a valuable exercise that promoted health and skills in self-defense. This trend provided a career opportunity for female (and male) pugilists to make money teaching boxing to middle and upper-middle class bourgeois (Gems and Pfister 2014). Sparring was a known fitness regimen for famous actresses, and in 1886 multiple papers wrote about a

¹⁰ Wilkinson is sometimes billed with the last name Stokes due to her marriage to less popular pugilist and boxing club owner James Stokes.

boxing school for teenage girls to learn the art of pugilism, not prizefighting: “There was no winner and after the bout, the girls discussed their tactics and mistakes like two military officials” (Jennings 2014:37). Many publications at the time refused to acknowledge female professional boxers, and the tone of the articles in those that did were not always approving but occasionally enjoyed mockery and scorn of the “gentler sex” pugilists. Unfortunately, this treatment of female athletes as lay players or jokes is one that continues today.

After WWII, American boxers returned home to find a drastic shift in their profession. With the advent of televised fights that people could watch at home for free along with other sports like night baseball, boxing clubs began going out of business and the entire economy of fighters, managers, matchmakers, etc. crashed:

The public tastes were changing. And boxing had a stigma to it, what with all the newspaper guys writing about fixed fights and investigations. It wasn't something a guy wanted to be a part of anymore. And the people in the neighborhoods didn't make fighters heroes like they had with the Jewish and Italian fighters who came from the Lower East Side, Brooklyn, or the Bronx. [Silver 2008: 78]

Around the time that many of my research participants were growing up, the sport of boxing was entering a downward spiral. Less violent sports appealed to families, and the role of the boxer as idol or protagonist diminished greatly. Current day boxing is an entirely different story in which multiple competing governing bodies have diluted the meaning of champion titles (Gems 2014). The trend of challenging opponents publicly and trash-talking has persisted with the most recent generation of celebrity (“influencers”) strapping on the gloves alongside professionals in sensational pay-per-view events. The agents and special interests that moved the sport of pugilism into the newest century are entirely distinct from those that advanced the reputation among the Parkinson’s community. Even so, there are distinct parallels between the sport and the therapy, particularly in terms of the skill set and emotional outlet that it provides the fighter.

Additionally, it is this backdrop of boxing as antagonistic sensationalism from which many of my participants entered the scene.

3.1.2 Boxing and Parkinson's

Parkinson's Disease and boxing have a dynamic relationship. It is now widely recognized that head injuries are risk factors for developing neurological conditions including Parkinson's and dementia. One of the most famous boxers of all time, Muhammad Ali is also one of the most famous people to have Parkinson's. Another famous boxer, Freddie Roach, is now using his training to slow down Parkinson's progression when it was likely a contributing factor to the initial disease development. Most of the individuals with whom I've casually discussed my research have a similarly confused reaction to the effects of the relationship between boxing and Parkinson's that I'm studying. "But... doesn't boxing..." is a fairly common phrase I hear from individuals with a basic familiarity with the disease. Rock Steady and other programs that train Parkinson's fighters engage in "non-contact" boxing and do not include hits to the head or body. Non-contact is a slight misnomer, however, in that fists make a lot of contact with bags and pads. Styrofoam pool noodles are used to indicate an opponent's movements, for example, a swing above the head of the fighter or tap where a blow would have landed. As far as headshots are concerned, however, there is no contact made.

A considerable amount of research has documented the effects of different types of exercises and physical therapy interventions on the speed of disease progression and quality of life among people with Parkinson's (Goodwin et al. 2008, Cruise et al. 2011, Combs et al 2013, Larson et al. 2021). Forced-rate exercises (one-third more exertion than voluntary rate) have been shown to produce a 35% improvement in PD symptoms after 8 weeks (Ridgel, et al. 2009). High-intensity exercises such as boxing enhance neuroplasticity and increase expression of

“neurotrophic factors such as brain-derived neurotrophic factor (BDNF), which supports the survival and production of dopaminergic neurons in the basal ganglia, improving overall disease severity” (Sangarapillai et al 2021:769; Ahlskog 2011). Boxing, in particular, requires the development of optimal body control and mental focus, featured impairments of Parkinson’s (Wilson 2018). Holistic training of any fighter requires addressing many of the same skills that the disease attacks.

Rock Steady Boxing is a program specifically geared toward training people with Parkinson’s in pugilistic pursuits. It was initially created by a former Golden Gloves boxing champion Vincent Perez who felt it would be helpful to his friend who had been diagnosed with Parkinson’s at the relatively young age of 40. He must have noticed something about his friend Scott Newman’s movements and struggles that resonated with his training because teaching him to fight brought profound physical and mental benefits “without adding a single microgram of the side-effects-ridden medication for Parkinson’s” (Young 2016:12). In 2006, the pair decided they could not keep this practice to themselves, and with the help of private donations, they opened a small gym free of charge for people with Parkinson’s to have a safe space for regaining self-confidence.

At Rock Steady Boxing, stretches are used to help with muscle stiffness. Footwork promotes balance. Punching serves to steady the tremors. Yelling strengthens the vocal chords, and hitting focus mitts encourages better coordination. “Boxers and clinicians alike say that they can see a vast improvement in motor skills, speech, and sensory function” (Young

2016:loc.118).¹¹ Since then, an entire trainer certification program has been created under the guidance of former second-ranked, world champion boxer Kristina “Kristy” Rose Follmar. Fighters with and without PD have traveled to Indianapolis to learn official Rock Steady Boxing methods and brought the program back home to cities around the world. Other boxing for Parkinson’s programs have sprouted up in gyms and community centers that replicate Rock Steady and boxing has gained recognition in the Parkinson’s community as a valuable tool in the fight to slow progression and control symptoms. Movement specialists and physical therapists recommend boxing to their patients.

This level and amount of exercise is effective in fighting a frequent comorbidity as well, depression. Plenty of research has demonstrated the physiological benefits of exercise on proper cognitive functioning and mood. Rosenberg et al. demonstrate that a regular routine of exercise games leads to a significant improvement in “depressive symptoms, mental health-related quality of life, and cognitive performance” (2010:221). For some, the ability to fight at all is a spiritually affirming experience. As one man shared, “if you fight it, you’re doing something, you’re taking control. And being in control is to me an antidote to depression.” Even on days he does not feel like boxing, he gets himself to do it because he knows that he’ll feel better afterward. He is not only covertly aware of this fact like an encouragement one might hear from a compassionate coach, his muscles and self-awareness have internalized this knowledge such that it has become embodied wisdom. I saw this embodied wisdom all over the gym: in part, a stubborn refusal to quit, but more than that- an awareness that their experience was a construct of their belief system. An idiom shared by many fighters was: life is what you make of it. They didn’t give up

¹¹ While vocal training is not a priority for most boxers, a loud gym makes yelling feel like a natural addition to the program while exercising vocal cords.

in the past and achieved great heights in their professional lives. There will be setbacks. There will be bad days. Those will be temporary too.

3.2 Finding the Gym

Considering the known connection between Parkinson's and boxing through figures such as Muhammad Ali, it may seem surprising to see the sport offered as a recourse against further progression. In the Parkinson's community, however, the reputation for boxing as one of the most effective interventions out there is rapidly growing. It fits the inspiring American tale of standing up to the bully who threatens independence. Multiple news stations have reported on Rock Steady Boxing, bringing more fighters to the gym. Many fighters did not expect to ever learn how to box, nor had they been interested in the prospect. Some joined the gym because of their doctor's recommendation; others were brought by a friend or spouse who had heard good things. They kept coming back on their own, however. One pair of ladies – Sultan of Smiles and Challenger – have been friends for a long time, even raising their kids together. The more daring of the two (Sultan of Smiles) was diagnosed with Parkinson's first and found her way to the boxing gym. After feeling the benefit of the classes, she called up Challenger, who was out of state visiting family, and said, 'when you get back to California, we're going to box!' Challenger was surprised and apprehensive about the prospect. 'Box?!' she replied. 'Me?! Nah! *You*, maybe, but *me*?!' Of course, she let her friend take her to the gym and found it shockingly empowering. As enjoyable and helpful as it is, she admits that it would be much less enticing or comfortable if she were the only woman at the gym and dreads the days that other lady boxers might be absent.

Developing a passion for the boxing aspect of training comes as a surprise to many of the fighters, who had not previously been drawn to the sport and entered with ambivalence over the perceived violent nature. These are people who had always fought their battles outside of a ring

(e.g. political arenas, courtrooms, military), and boxing had never been relevant to their identities before. Parish notes, “What people typically seek are relevancies to life and self, where “relevant” reflects experience, in the present” (2008:45). As other arenas became less inhabitable for their neurodivergence, the practice of pugilism came to symbolize the struggle for relevance.

Coach himself credits the group for helping him build his gym and giving it a life in the first place. He was doing an outdoor boxing boot camp when two women approached him about creating a Rock Steady Boxing (RSB) program in San Diego. They were so demanding that Coach found himself in Indianapolis training to be an official RSB Coach. The class started in a park before moving to a shared space in a downtown San Diego boxing gym but quickly grew in popularity. Before long, Coach was able to open his own gym. There are a few trainers and programs for people with and without Parkinson’s, but Coach devotes the majority of his personal efforts to his Parkinson’s fighters.

3.2.1 Demographics and ethos of gym

While the atmospheres at boxing gyms vary greatly depending on the head coach (Wacquant 1995: 492), it must be rare to see one with such positivity, gratitude and optimism. This particular Parkinson’s boxing gym has more female members than many of the others, though they are still in the minority. Many of these individuals grew up with an emphasis on hard work, productivity and grit. San Diego has a strong military presence, and many of the fighters grew up in military families, were in the Navy or were drafted to fight overseas. All of the fighters with whom I spoke were enculturated into an ethos of determination, mind over matter and community engagement. At this point, many of the fighters are retired, but each individual in the group has an impressive occupational history, and many still contribute to various efforts through arts, education, volunteer work, fundraising and more. There are high

levels of gratitude within this group, and fighters are aware of the privileges inherent in the opportunity to give back to the community and engage meaningfully. Although we all face a potential future of dependence, many of us can focus on more favorable possibilities. Being diagnosed with a progressive motor disorder narrows these avenues of healthy aging and demands a concerted effort to maintain and promote well-being. Staring down undesirable outcomes can cause a person to freeze and withdraw; however, it can also inspire a realization of the abundance of one's current capabilities. This is an effective seed for gratitude as well as motivation to use those current capabilities. In the previous chapter, I demonstrated how many fighters experience an initial episode of depression after the diagnosis. For some, this depression never fully leaves, and for some others it comes and goes. The trick seems to be holding on to the knowledge of abundance while moving forward acknowledging the depression's presence but not stopping for it.

Documented health benefits have not been enough to grant Rock Steady Boxing status as a medically reimbursable physical therapy practice.¹² Despite the similar socio-economic statuses and primary language (English), ethnically, the gym is extremely diverse (including Latinx, Asian and Black Americans). That said, the majority of fighters identify as White Americans with family origins ranging from Italian and Mediterranean to Nordic and Anglo-Germanic. Class sizes vary by the day but are frequently around 25 fighters. Classes are majority male, and I have never seen a class made up of more than one-third women. Though it is not terribly common, there is always the chance of being the only woman to show up at a particular

¹² Some insurance companies partially compensate for gym memberships, however I do not know if any of the fighters take advantage of this.

class. This does not bother all of the women, and I never took an official count but both opinions were expressed at various times.

Overall, there are well over 65 people in the program, with most fighters attending at least a couple of classes per week. Some attempt to come on less busy days, and Coach is conscientious about helping all fighters find space and time to train without feeling overwhelmed. At the beginning of my fieldwork, two classes were being offered per day at the gym, but after the COVID-19 pandemic broke out and the world entered lockdown, the program switched to a once daily virtual format (over teleconference software Zoom). After the lockdown was lifted, some fighters had grown accustomed to the virtual arrangement and were appreciative of being able to box without needing to drive to the gym. Coach began to offer one digital class in the morning and an in-person class in the afternoon.

Initially, I was uncertain about the line between encouragement and pushiness. I'm not a physical trainer paid to yell at a neuro-typical athlete and shape their workout experience. I'm an anthropologist hoping to learn about the experiences that they're already having. I figured that these individuals probably knew their limits and may not be happy with them. I didn't want to point out a mistake if the person was doing their best, I thought. But when I heard Coach doing so, I asked what I should do when a fighter was only using one hand or not moving in a specific way. He was emphatic that we should encourage them to follow the exercises as closely as possible. While the gym is an arena to address physical limitations, the only way to do so is through confronting these limitations. Staying aware and cognizant of what the body is and is not doing becomes increasingly harder as the disease progresses. The ethos of the gym is one of determination and tenacity, but it is also honest. It is there to help bring awareness back to bodily sensibilities. Ignoring problem areas is counterproductive. As it turns out, forced use of limbs has

been seen to improve mobility and delay Parkinson's progression in animal models (Tillerson, et al. 2001).

For the fighters who join the gym and become regular members, the continued use of the gym and relationships that are developed create an empowered sense of community that provide an opportunity to be understood by an entire group of people at once. Still others find the reminder of their possible futures too unsettling to be therapeutic. For these individuals, the view of their potential future is unbearable, and they are not likely to return. I asked Coach if he had considered creating two different classes to accommodate the wide variety of symptom severity. He had heard the question before and knew that he'd possibly lost potential clients who had hoped for this option but he was set in his conviction. If he were to do that, he would just be doing the same thing to the advanced stage fighters that everyone else does- separating them. Equally importantly, we would miss out on the wisdom and value that they have to offer the rest of the class. This was their chance to still be part of the crowd as a full, contributing person and he was proud to provide that opportunity.

3.2.2 The Gym in the Community

The Parkinson's community has a well-organized and strong base in San Diego, CA. The Parkinson's Association of San Diego (PASD) throws annual events like "Empowerment Day" and a 5k walk where people can find resources, network with research studies and Parkinson's-oriented services, and show their support for one another. The gym facilitates participation in these events, and fighters team up for walks and fundraising efforts outside the ring. In this way, bonding that occurs at the gym permeates the social world of the fighters.

The gym too has traditions that build community, pay tribute and have fun. One such example is the annual gym tee-shirt personalized with each fighter's name on the back. In 2020,

the tee-shirts were black with a yellow inscription on the front stating “ALL YOU NEED IS LOVE AND BOXING” above a silhouette of a boxing ring. Coach gave me and Maven of Misery, one of the trainers our shirts at the same time. She commented on how much she enjoyed the nicknames and shirts. Boxing is not a team sport, and she had never had the chance to feel that level of athletic comradery before working with the Parkinson’s fighters. At the anniversary party and holiday party, pictures from throughout the years are played on televisions in the background, jokes are made and everyone joyfully relishes in one another’s accomplishments.¹³ A memorial slideshow plays pictures of fighters that have passed away during the year and everyone takes a moment to reflect on their fallen friends. “Not a bad way to be immortalized,” commented Dynamite.

When a fighter passes away, they receive the fallen boxer’s ten-bell salute in addition to being featured in the above-mentioned anniversary party slide show.¹⁴ Typically, this takes the form of a video and photo montage of the person’s time as a boxer (and sometimes before) with ten consecutive bell rings sequentially playing in the background. Some families make an effort to share the memorial service information in time for the fighters who wish to attend. Occasionally, the gym will not be notified of a fighter’s passing right away. People might reach out to the family and quietly spread the word with others who inquire, but there is a strong respect for the family’s wishes. At these times, I pondered whether their fighter identities were

¹³ Some boxers bring family and friends, others come on their own.

¹⁴ The ten-bell salute is tradition within the boxing and wrestling communities to honor a fighter who has passed away. This may be through meditative moments of silence for ten counts as a bell is rung at the end of each beat at a gym or before a match, or in a more multimedia modality incorporating videos and photos of the deceased which can be found on various social networking sites and played at televised events.

the last to go and if that might have played a tiny role in the families' reluctance to share the news. But that is likely just the poet in me.

In addition to the social elements, physical therapists and healthcare professionals give talks about relevant Parkinson's topics (such as Deep Brain Stimulation surgery and constipation) leaving time to answer questions. This is a valuable resource for people to have specific issues or concerns addressed that may not occur to them at the doctor's office. There are conflicts of interest that arise with some of these individuals being reimbursed by services that they are discussing. Generally, this was not too concerning for the fighters who are historically independent thinkers, but at least one fighter expressed slight suspicion about the ulterior motives of a particular out-of-state speaker.

This section has introduced the lifeworld of the gym and illustrated the quotidian rhythms of engagement among fellow fighters and the community. From here, I will continue the journey towards developing a Parkinson's fighter identity by exploring the motivations for choosing this health modality and internalizing the ethical subjectivities of boxing. I demonstrate what this practice provides people with Parkinson's that is hard to find elsewhere.

3.3 Motivation for becoming a fighter (and staying that way)

In the sociological tradition, Bourdieu asks why people choose different sports and calls attention to the conditions of possibility for acquiring an athletic skill set, and the social acceptability of any given sporting occupation for the potential athlete. In *Sport and Social Class*, Bourdieu hypothesizes that sports are "offered to social agents... as a *supply* intended to meet a *social demand*" (1978:820) and asks how people acquire the taste for one sport over another. Likewise, we can consider how people commit to a specific style of physical therapy.

This is particularly curious when the physical therapy in question employs a sports product that was not previously of interest or relevance to the athlete. According to Bourdieu, developing an interest in certain “elite” sports is in part due to the desire to engage with its “distinguishing function and, more precisely, to the *gains in distinction* which it brings” (1978:828).

While physician recommendations and data are convincing reasons to try out a new regimen, other easier or more familiar programs may offer similar benefits. Provided the recommendations and news stories are convincing enough to get a person through the doors of a gym, what makes them come back? This section explores the reasons that fighters continue to participate in boxing training and how the seemingly straightforward process of acquiring boxing skills is infused with opportunities for healthy social engagement and self expression.

A unique constellation of reasons is required to appeal to the complex needs and preferences of any one person. Citing Douglas Hollan, Kaiser and Fils-Aimé write:

individuals differentially draw on cultural resources—like sent-spirit narratives—for several reasons, which might have to do with the particular experience of misfortune, their resulting affective states, and their ability to tap into cultural meanings to achieve “symbolic transformations of painful emotions” (1994:74) [2019:16].

In addition to the health benefits that initially inspire a person to give boxing a try, there were three key reasons expressed by my research participants. First, the ability to change the narrative from one of being a Parkinson’s patient to an active fighter which better fits the continuity of a biographical narrative of which they approve. Second is the ability to release frustration through physical exertion. And third is the relationships developed at the gym between the fighters and the coach.

By joining a boxing gym, a female fighter is not trying to be “one of the guys” or get in touch with her “purified and magnified masculine self” as Wacquant has described the character

of prizefighting boxers (1995). These women are cultivating a fighting spirit and expressing their determination and independence, two characteristics that are by no means particular to men. The physical act of being able to throw a solid punch and acquisition of boxing knowledge is an amusing side effect of their training but also nurtures a sense of physical empowerment that can be hard to find in later life. Influenced by the cultural expectations and personal values of productivity, they are actively working against the decline narrative and fashioning a heroic self that demonstrably fights to delay progression and stay active as long as possible for themselves and their families. In this group, this is what an ethical woman does; she fights for the health and wellbeing of herself and her community.

3.3.1 Changing the narrative: from patient to fighter

Unfortunately, the way that Parkinson's is presented to the patient initially and considered by the medical imaginary could have harmful consequences on the health outcomes of patients. Learning a new skill like boxing allows them to prove that although they are now living with Parkinson's, they are still living and importantly, still living as themselves and not as a degenerated version of themselves. It also allows people to change the narrative from one of a Parkinson's patient to a Fighter. In one of our female fighter conversations, a woman shared about boxing: "It makes me feel badass. You know, like, I'm not an old lady with Parkinson's. I'm a boxer. So I like that. That gives me confidence." Another woman agreed that "it gives you a different way to identify yourself" and remarked on how much better it feels to answer questions from her friends and family about how her boxing is progressing than how her Parkinson's is.

The gym also offers an opportunity to change the aging narrative from one of decline to one of skill acquisition and growth. Motor disorders and age-related diseases alter the biological

trajectory and speed of typical aging processes. More distressingly, such diagnoses carry the potential to alter the way friends and family perceive and treat people with Parkinson's. Awareness of the complexity that their condition adds to the fabric of family life is particularly high. Hodgson, et al. observed "worries for children developing the disease, uncertainty in future plans, and financial obligations were more characteristic of couples affected by PD than in general chronic illness" (2004:23). An intervention that can help a person "stay ahead of it" – as boxing has proven to do, is both physically and symbolically valuable to a person's subjective experience of being an ethical person and responsible family member.

3.3.2 Productive transformation of frustration

"If it wasn't for boxing, I'd be in jail by now;" Moxie believes she would have punched somebody out from sheer frustration or anger. Dynamite concurs vehemently. It is not easy to wrestle with the daily difficulties of chronic diseases. Many individuals feel frustration with the nuances of performing activities of daily living and the social challenges that arise with Parkinson's- these can include everything from overt stares and discomfort about a visible tremor, the weakened vocal cords making it difficult to have conversations in loud places (or behind masks) to insecurity driving and medication timing. The physical experience of hitting a bag was able to mitigate these in a way that was deeply missed during the many months of online classes that were necessary during the COVID-19 pandemic lockdown. While there were benefits to online training (which I will discuss further below), the ability to "punch something" was often reminisced over and longed for.

Moxie's comment about boxing keeping her out of jail is a common sentiment expressed by proponents of the positive social and community benefits to people susceptible to violence or gang culture who spend time in boxing gyms as opposed to on the streets. Pugilism provides a

pro-social and culturally-acceptable manner of releasing frustration and anger. Gordon Marino (2010) opines that boxing “makes people feel more at home in themselves, and so less defensive and perhaps less aggressive.” Having an outlet for frustration allows people to expel the angry energy that is otherwise socially unacceptable to reveal. This is particularly beneficial to structurally vulnerable individuals who are unable to directly challenge their offending parties. Here we see that it is not just social structures that can violate a person’s experience of self-fulfillment and autonomy but neurological structures as well. People with Parkinson’s are fighting attacks on both fronts: their neurology and social personhood are under threat but boxing offers a resource for empowerment that allows the body and embodied mind to cope with these challenges.

It is natural for an older group of adults to see members disappear for weeks at a time while they recover from a fall, surgery or other complications of aging with a chronic condition. As healthy as they are, this group too sees its fair share of accidents and illnesses that complicate their participation in boxing. For some, a recovery period that prohibits boxing is even more dreaded than the health complication itself. During one of our online ring-side chats, the conversation turned towards how the boxing program has saved lives. One male fighter explained:

To have something to look forward to, in fact, I had- I kind of did something to my shoulder the other day. It's a lot better, you know, but I got worried. I was actually having a real panic attack that I might have to stop doing Rock Steady Boxing, and that that was not good. So you know, everybody needs to take care of themselves for this.

Even though boxing was started to take care of Parkinson’s, the fighters began feeling a need to take care of themselves for the boxing. Having the opportunity to connect with a version of the self that is ethically heroic and socially engaged has positive effects on self-esteem and

can improve the outlook of individuals who suffer from uneven physical experiences. Another fighter agreed, sharing that he'd had a pacemaker replaced a few weeks previously: "I had to be off boxing for a couple of weeks and that was the worst part of it. Yeah, pacemaker is no big deal. It's missing the boxing." What is missed is the embodied social action that defines the self as a continuing participant in their own lives. Not boxing means losing an avenue for communicating the heroic self that one has become and reinforcing a sense of determined wellness that is constantly called upon in the management of Parkinson's disease.

3.4 Relationship to Coach and each other

As Jason Danelly notes, "In anthropology, informal economies are central to understanding social practices on the ground, since exchange relationships are always loaded with symbolic meanings that cut across social domains" (2015:27). Individuals within a culture process meaning through these exchange relationships to inform or reinforce socially derived information on the macro-level (such as group standing) as well as in more intimate domains that regulate emotional and behavioral responses. While Coach credits the fighters for giving his gym life in the first place, the fighters are endlessly grateful to him and the program. Multiple fighters expressed the belief that the coach, trainers, and other fighters have saved their lives.

When participating in high-intensity training with a movement disorder, it is essential to keep the trainer informed about the physical and illness experience. As tough as the classes are, Coach's approachable and compassionate demeanor creates an environment in which many fighters feel comfortable asking his advice and knowledge about certain aspects of the disease. While he never gives medical advice, Coach connects different fighters who are experiencing similar concerns with each other and various resources in the community.

Even though they pay for a membership and this gym is technically a business, it feels like a family showing up to support one another, which includes Coach's gym. During the pandemic lockdown, when the gym had to shut down for an indefinite amount of time, fighters continued to pay their membership fees to support Coach, the staff and the gym. At the last three Christmas parties (and probably many more before that), the fighters presented Coach with a monetary gift that perfectly fit the American model of a holiday bonus. Actions are carefully orchestrated according to business cultural scripts, but the emotions that motivate them are entirely genuine, familial and even intimate. There is a real concern among the fighters that Coach will not fully appreciate the level of gratitude that they have for him and the classes. They joke about how well he knows each one of them and for the 2020 year-end party (which occurred on zoom), one of the fighters prepared an entire short film parody about Coach's life to level the playing field.

Coach employed multiple techniques to create a sense of unity and focus during the lockdown. There were a couple of benefits to moving online. For one thing, classes could be recorded and re-watched at other times. This was greatly appreciated by the fighters who dreaded finding other exercises to do on the weekends when classes were not offered. Another tactic that contextualized their efforts within the boxing world, despite the lack of a boxing gym, was the creation of themed weeks in which a particular pugilist's technique and fighting style was emulated. Each day, Coach would send out an email summary of the workout along with a link to the recording (excluding the ice breaker conversation) and a link to a YouTube video of the day's moves in action in the ring. Occasionally, Coach was able to emulate a boxer who had an upcoming fight. When this occurred, Coach held virtual fight nights at which he could point out the moves that they had learned and explain strategic choices. This demonstrates how ingrained

the culture is within the boxing world itself. It is not just physical therapy with a nod to pugilist techniques.

Another benefit of the virtual classes has been the level of accessibility. Many people with Parkinson's end up losing their driver's licenses and relying on family and friends or ride-sharing services for transportation. Classes are also held during weekdays, which has complicated things for people who are still working or have younger families that need attention. Getting to the gym every single day to work out is simply not possible for everyone. Being able to tune in and re-watch the recordings later has allowed some of the less frequent fighters to engage in the gym on a whole new level and feel included in a support system that understands the variety of challenges they face in an ordinary day. One relatively new member, Highlander expressed feeling that the group had taken on a fictive family role in her emotional support:

With going on zoom, I feel like we've become more like a family. I don't know how to describe it, but I get a little emotional about it. And I apologize, but I just felt like I was only going on Fridays at 10 [a.m.]. So I just saw the people there at 10. And now I feel like we're connecting and I just feel closer to people and, and that helps a lot too, just the emotional part of it. And knowing that you're not the only one with PD, these are other people with PD at all different stages, you have lots to learn from them. And this group just seems to be so open and sharing with everything and it really makes a difference for me.

As supportive as family and friends are, they were unable to provide Highlander with the type of empathic resonance that other fighters with Parkinson's afforded. I will expand on this phenomenon further in the following chapter.

3.5 Ethical Subjectivities

“Inside of the ring or out, ain't nothing wrong with going down. It's staying down that's wrong.”

– Muhammad Ali

3.5.1 Morality of boxing

There are plenty of ethical issues surrounding the sport and economy of boxing, not least of which is the treatment of the fighters themselves. I'm not referring to the boxing match itself, rather the economic and social manipulation that results in chronic conditions without enduring healthcare. While these behind-the-scenes machinations are the focus of certain critiques, many others take issue with the practice of pugilism itself (Wacquant 1998).

After Loïc Wacquant's ethnographic research among prospective prizefighters in late 20th century Chicago's South Side, he disputed the popular discourse of boxing as a glorification of violence and spoke of the "*positive moment of pugilism*, that spelled by craft, sensuality, and morality" (1995:490). To the skilled fighter, boxing is equal parts mental as it is physical. It involves self-mastery and emotional control. For a professional pugilist, fighting outside the ring or with an individual who is not appropriately trained is strictly forbidden. Well-known fighters may travel with a bodyguard to avoid altercations with lay people who seek to cause trouble or walk away with a good fight story. While the "*specific honor*" of this sport is the refusal to back down, there are strict parameters surrounding ethical behavior and appropriate modes of resistance. Giving in to the provocations of an unskilled instigator outside of the gym is not an honorable response; rather controlling aggression demonstrates self-mastery and respect for their boxing craft. Within the ring, "A pug who quits in the midst of battle is branded with the mark of infamy and suffers a veritable symbolic death" (Wacquant 1995:496). This tenacity is not simply a stubborn refusal to quit but an expression of commitment to the betterment of one's self and contribution to the community while facing threats of devastation:

Fighters conceive of boxing not as a springboard for aggression and an exercise in violence but as a skilled bodily trade, a competitive performance craft requiring sophisticated technical know-how and an abiding moral commitment that will enable them not only to improve their material lot but also, and more urgently, to

construct a *publicly recognized, heroic self*. Boxing is the vehicle for a project of *ontological transcendence* whereby those who embrace it seek literally to fashion themselves into a new being so as to escape the common determinations that bear upon them and the social insignificance to which these determinations condemn them. [Wacquant 1995:509]

For both professional boxers and Parkinson's fighters alike, boxing represents an idiom of autonomy with which the individual expresses a resolve to control (or at least influence) their fate. Amid a disadvantageous system, be it a socio-economic or neurological system, the practice of pugilism offers an avenue for active self-determination and social empowerment. This aligns with the moral subjectivity of the United States such that boxing meets a "social demand" in the Parkinson's community.

Boxing gyms are well known and researched as spaces for self-transformation (Owton 2015, Kosiewicz 2018). Fighters do not believe that learning to box will cure Parkinson's, but there are real embodied experiences of it improving everyday life and functioning significantly. Like Wacquant's prospective prizefighters, these boxers devote their energy to the craft because it offers "not so much an opportunity for economic betterment as the promise of *social difference and even transcendence*" (Wacquant 1998:328). The boxer starts at a low point in life and is looking to mobilize their potentiality. They are looking for a re-orientation of their experiential selves as well as their social personhood. This requires an existential risk; the payoff being a chance to reassert control over one's life circumstances.

Beyond this, philosopher and boxing trainer Gordon Marino (2010) argues that "boxing provides practice with fear and with the right, attentive supervision, in quite manageable increments." Increasing exposure to situations that trigger fight or flight responses allows that individual to see through their emotional experience more clearly to recognize opportunities for forward momentum. Fighters learn not to panic when faced with the harsh challenges of life.

3.5.2 Parkinson's Subjectivity

Parkinson's is unpredictable. While there is a particular genetic mutation that leads to Parkinson's, this accounts for less than 10% of the cases, and very few individuals screen for the trait. The progressive aspect forces fighters to re-consideration of future plans according to an unknown timeline. Adding to this ambiguity is the constant surprise of which symptoms will appear as the disease progresses. Aside from the hallmark issues of slowing, rigidity and loss of balance, there is a menu of possible Parkinson's side effects that do not affect each person. Not only do "continually shifting experiences of the body undermine efforts to repair disruption" but the management of such a disease "entails a continual reworking of identity" (Becker 1997:124). Repeatedly reinforcing the self in a body with Parkinson's is greatly facilitated by the alignment with a durable cultural model known for acknowledging and withstanding physical punishment: "Suffering alters the terms of our existence, and so alters the terms of subjectivity and selfhood, setting in motion a search for a response adequate to the suffering, which may also set in motion a search for a self adequate to the suffering, and to the response" (Parish 2008:127). The fighter self calls on cultural tropes of resilience, strength and determination in anticipation of abuse and amid disrupted bodily experience.

Sarah Lamb's description of the North American conceptualization of the "individual self as project" (2014) is well matched to notions of moral aging discussed by participants. Lamb notes how current paradigms of successful aging in the United States emphasize the ability of the individual to structure their lives healthily and productively to minimize their burden on society, healthcare and family.¹⁵ This self-empowering outlook also has an unfortunate effect of placing a

¹⁵ Lamb contrasts this with areas of India in which older adults experience a "meaningful decline" and are not expected to maintain high levels of cognitive and physical functioning towards the end of life.

large amount of responsibility on the individual to maintain levels of functioning that may not be entirely reasonable to expect of an aging body. Parkinson's Disease creates an additional challenge to maintaining the levels of engagement and productivity that were familiar to younger selves. Parkinson's fighters work to be seen as still evolving and aging successfully despite their diagnoses. Boxing is not just a health intervention but a moral exercise that imbues the body with an ethical subjectivity. Multiple participants expressed the US American sentiment that with enough willpower, one should be able to maintain control over the mind and body. As one fighter shared, "You have to, you know, they say you become what you think - you are what you think. And you know, you have to control your mind. You have to tell your frontal cortex: You're the boss." While Parkinson's forces the recognition that one cannot always exercise bodily control, some maintain an expectation that the mind will reside under the domain of a strong will. A frequently shared anxiety concerned the loss of mental acuity.

Boxing aligns well with what Cameron Hay refers to as the "John Wayne Model" of coping with illness: "The John Wayne Model legitimates and offers a script for what one should do when ill: be productive, systematically tick off boxes, not complain, and work unhaltingly—within biomedical or alternative health care traditions— to control one's illness" (Hay 2010:269). This approach to illness is not only regarded as ideal behavior but expected from moral citizens further marginalizing individuals incapable of sustaining this level of engagement. With the high moral value placed on productivity in the United States, researchers of chronic illness experience have noted the imperative placed on the individual to regain health and typical functioning (Parsons 1953, Parish 2008, Hay 2010). As a degenerative illness without a cure, the aim for people with Parkinson's is to delay progression for as long as possible. This fits another model seen within the successful aging movement and literature, "compression of morbidity"

(Moody 2009), which posits a responsibility on the individual to minimize the more burdensome aspects of disease and disability.

3.6 Idioms of resilience

Cultural resources are mobilized to provide protective factors against psychoses (Myers 2015) and to form a “resilient protection of self in the face of enduring lack of agency” (Kaiser 2019:383). It is important to recognize that cultural resources are not a panacea and that certain types of pain may be persistent despite therapeutic intervention (Hollan 1994:175). The strategies that work well for my participants cannot be implanted anywhere or with just anyone, but this ethnography allows us to look at the mechanisms at work in cultivating a new “stylistics of existence” (Foucault 1988) later in life in such a way that an individual benefits from the values that the cultural practice nourishes.

Anthropological conceptions of idioms of distress have contended that communicating personal suffering in a culturally-meaningful manner works to articulate the effects of socio-political forces that have either led to the distress itself or have heightened it through the cultural understanding of the disease. Engaging idioms of distress can have the effect of perpetuating the systemic issues in place (Cassaniti 2019). In a special issue of *Transcultural Psychiatry*, Kaiser and Weaver encourage scholars to attend to the social and structural forces shaping idioms of distress to avoid the pitfalls of an overly myopic analysis such as victim-blaming (2019:594). Anthropological and cultural psychological research has more recently begun to address cultural practices of resilience¹⁶ that express wellness and positive coping in the face of distressing

¹⁶ Resilience has been described as the ability to “adapt successfully” (Masten 2014 cf. Jenkins and Stone 2015) however it’s important to remember the level of subjective implicated in the understanding of success.

conditions. Resilience is often defined as a positive psychological adaptation amid suffering (Kim, et al 2019). While suffering has been an important area of research for social and behavioral scientists, Kim and colleagues argue that “the complementary range of resilient responses” (2019:721) has been largely overlooked. This research identifies the process of becoming a Parkinson’s fighter as both an idiom of distress, and a healing modality that generates resilience. Suffering is a dynamic social and emotional experience, and as such it opens the opportunity for multiple avenues of development, not least of which is moral development.

Pugilist ethics of grit, tenacity and toughness match dominant US cultural ideals allowing what may have been a previously dissonant cultural practice (boxing) to act as a vehicle for performing a consistent moral self: Moral because the self acts against the decline and degeneration narrative that accompanies Parkinson’s and consistent because it demonstrates a tenacious and productive intentionality familiar to that of pre-diagnostic selves. Boxers must first and foremost get back up after a knockout. Resilience is not only recommended; it is required. In fact, any boxer “who quits in the midst of battle is branded with the mark of infamy and suffers a veritable symbolic death” (Wacquant 1995:496). The symbolic life of the boxer is encapsulated in the resolve to never give up. Losing a match is not a defeat as long as the effort was there. To quote Muhammad Ali, “Inside of a ring or out, ain’t nothing wrong with going down. It’s staying down that’s wrong.” In embodying boxing ethics, they are directly teaching their bodies not to give up the fight.

In her work with Tibetan refugees in India, Sara Lewis demonstrates that with “mind-training” (*lojong*), individuals can cultivate a sense of agency after periods of political violence. By freeing their minds of negative emotions, they refuse to be internally dominated, cultivating a

sense of ownership over their own internal space. Lewis has characterized this process as generating “inner agency” which is especially valuable in times of structural uncertainty (2018:354). When there is little about one’s circumstances that can be changed, the use and direction of one’s attention and mental energy is a vestige for agency. One fighter shared a sentiment expressed widely by Tibetan refugees quoting His Holiness the Dali Lama, “Worry just ruins today and tomorrow. You know, worrying doesn't fix anything. It just screws up today.”

As mentioned, the phenomenology of Parkinson’s has been described as “sharing space” within the body, and multiple fighters spoke of boxing and physical activity as liberating a sense of internal space. In this sense, we can see how training the mind and training the body are “agency making” practices that should be considered within the range of resilience responses that have been often underappreciated in the larger discourse of human suffering. Focusing on the present circumstance helps fighters avoid catastrophizing about undesirable possible outcomes. At the same time, knowledge of a quickened aging process (to put it in the mildest terms) adds an underlying sense of urgency to live life fully within the moment. This orientation shifts dramatically depending on an individual’s age and working status. For the younger fighters who have yet to consider retirement, the time after diagnosis but before the more debilitating symptoms set in (the “honeymoon period”) is a time to get their lives in order and either amp up productivity or rethink their subjective experience of a productive and meaningful life. The gym provides a home base within the Parkinson’s community through which a meaningful post-diagnostic identity of resilience and engagement is made possible.

3.7 Conclusion: boxing as a technology of self continuity

Simone de Beauvoir posits that creating themes through life allows a person to navigate the ambiguity in a present moment: “If I leave behind an act which I have accomplished, it becomes a thing by falling into the past. It is no longer anything but a stupid and opaque fact” (1947:27). After the artist pours their self into a project, desiring an end is suicidal. They must find ways to integrate the past, to lean on their “anterior creations” (1947:27). Finding the riffs in life’s rhythm and incorporating them into the current flow allows the composer to present an authentic voice and signature style while staying fresh and honest to the moment at hand. Parkinson’s Fighters have fallen out of rhythm with their former lives but found shared riffs with boxers. Going to the gym becomes not only a negotiated practice of agency, but a technology of self continuity. It does not matter that boxing itself is a new occupation for these fighters; the ethical subjectivity of fighting for the self in a competitive environment is familiar.

In this chapter, I have explored moral parallels between boxing and the mainstream culture of my research participants in California. This has enabled fighters to embody an ethical subjectivity that allows the “self as project” to carry forward the seeds of the “anterior creations” through boxing as a meaningful cultural practice. Beyond affording continuity of self, boxing and gym life create a community that supports one another’s physical and emotional health. In the next chapter, I will consider the process of acquiring a new embodied mode of connecting to dominant ethical subjectivities and demonstrate how this may provide protective benefits that slow the progression of disease.

Chapter 4 Into the Self

“Through the ministry of boxing, fighters’ ambition is to remake themselves and the world about them” (Wacquant 1995:510).

4.1 Introduction

The last chapter discussed notions of why an individual may be drawn to boxing as a therapy and what factors motivate their continued participation. In this chapter, I will be answering the question: how does boxing as a healing modality provide healing? After considering this group’s conceptualizations of healthy aging (or “successful aging” as it is often called in the literature), I will position this research among current theories of grounded cognition. Fighters beat Parkinson’s by not being beaten by Parkinson’s. They accept Parkinson’s as the adversary, but they continue to fight for space within their own bodies as the disease becomes a presence that disrupts their lives. Accordingly, this chapter explores processes of embodiment. It demonstrates how learning to box can offer additional protective benefits through the development of a subjectivity that emphasizes resilience and toughness. Training as a boxer aligns the self with culturally dominant ethical tropes of productivity and self-discipline (Kaufman 2011). Fundamentally, the community of Parkinson’s fighters offers a sense of belonging and a zone of empathic resonance within which individuals can ease their insecurities surrounding symptom expression and bond with others while learning a new skill and taking control of health outcomes.

4.2 Model of Healthy/ Successful aging

Throughout the animal kingdom, fighting is an expression of dominance. By returning to the gym day after day, my participants are exerting control over their life trajectories. Fighters

say that boxing empowers them by affording an active intervention to improve illness experience without the use of additional pharmaceuticals or medical devices. Boxing is something that does not need to occur within the realm of healthcare as a patient. It is not a passive operation but requires hard work and demonstrates social and bodily capital. It is an essential component of a successful, healthy aging experience. This chapter starts with a brief discussion about paradigms of successful aging as they are currently being discussed and as they apply to my participants.

I introduced the notion of successful aging in the previous chapter while discussing ethical subjectivities in North American cultures. Successful Aging was first outlined by gerontologists Rowe and Kahn (1997), who delineated three essential features for inclusion: 1) the avoidance of disease, 2) the maintenance of cognitive and physical functions and 3) continued social engagement. Since this proposition, numerous criticisms have been levied against the overly ambitious definition. Additional terms have been posited to include an element of subjectivity and widen the spectrum of individuals within this category, such as healthy aging, positive aging, and conscious aging (Moody 2009). This ethnographic account contributes to the literature on successful agers, who are thriving despite disease, and changing physical capabilities.

Most successful aging definitions focus on the avoidance or minimization of disease and disability. Dunbar has found, however, that a solid predictor of well-being and longevity is friendships and social connections (Dunbar 2018). Forming close bonds to others allows for positive engagement with the community and a boost to self-esteem: “Self-esteem is regarded as a key factor in positive aging... Self-esteem involves an affirmative interplay between the self and the external world (Featherstone and Hepworth 2009:140). Increasing opportunities for positive interactions between the self and world is a highly valuable characteristic of the gym.

The element of control is highly prized in the United States (Becker 1997, Hay 2010, Kaufman 2011, Lamb 2014), and my research participants expressed a strong belief in this value occasionally causing tension with the lived-experience of diminishing motor control. Boxers present an image of both peak physical conditioning and beaten bodies with a rhythm to their patterns of fitness. Parkinson's fighters can relate well to an identity that is forged amid repeated disruption and confronts the vicissitudes of fitness with determination. As Parish observes, people mobilize their subjective potential and cultural models in the process of coping (2008:126). While the cultural representation of Parkinson's is one of degeneration and weakness, boxing is conceptualized as calculated strength which according to participants boosts feelings of self-confidence and pride. Representing the self as a fighter to the larger community, the smaller gym and to other parts of the self can profoundly influence the embodied experience and cultivate resilience.

There have been a few fighters whose health complications interfered with their ability to continue regular training; however, they maintained an attitude of expectant return (whether or not they always believed it). For them, boxing has become a self-defining hobby that brings purpose to the experience of Parkinson's disease.¹⁷ Purpose in later life has been identified as an essential component to healthy aging and longevity by multiple scholars. Cultivating resilience was acknowledged by my participants as being hugely beneficial to the fight against Parkinson's. Binding an embodied feeling of determination and accomplishment to physical exhaustion provides a boost that helps with the additional challenges encountered during daily living with Parkinson's. This developed resilience in spite of repeated injury, changing physical capabilities,

¹⁷ Importantly, I am not suggesting that this makes Parkinson's worthwhile or preferable. Purpose is often generated through arcs of suffering.

mood instability and intense fatigue.¹⁸ Establishing a suitable and moral cultural model to combat the disease and maintain dignity makes Parkinson's an approachable challenge that can be acted upon and influenced according to personal values. In my work, boxing has emerged as an effective idiom of resilience. Fighters discuss their observation that many other diseases or disabilities are more "intractable" and just as random. Regardless of neurological status, they argue, getting old "is not for sissies." Were they not diagnosed with Parkinson's, they may not have acquired a model to effectively combat the negative stereotypes and challenges of aging. Several fighters even expressed a reluctant gratitude to Parkinson's for introducing them to boxing as a self-care practice. Operationalizing the resilience developed from Parkinson's may counter the negative stereotypes of aging or challenges to ego-integrity and self-continuity that develop over the years. This transference of resilience is one of the factors proposed to account for successful aging among lesbian and gay older adults who learn to question the dominant social paradigms that have previously worked to delegitimize their sexual identities. Friend observes, "Access to diverse models of what it means to be an older person is essential to this process of challenging stereotypes" (1991:111).

Psychological and medical anthropologists have famously demonstrated the interactions between emotions, morality and meaning-making (Lutz 1988, Rosaldo 1984, Throop 2010). Yang, et al. depicted how cultural norms and values are linked to emotional experience through what have been termed "moral-somatic processes": "In moral-somatic processes, one's bodily states are linked with one's experience of societal norms and values—i.e., the experience of the social world may be transduced to physiology" (2007:1531). Agency-generating idioms of

¹⁸ Interestingly, according to a poll online on PDnet, fatigue was cited as the most debilitating symptom of Parkinson's.

resilience may be effective ways of intervening upon the internalization of negative “social cognitions” (Barsalou 2008:630) and stereotypes that may otherwise be harmfully embodied (Levy 2009). While the experience of an expanded internal space that fighters claim accompanies boxing may not be a “durable disposition,” the repeated opportunities to embody that sense of self carry emotionally healing properties. A successful day training is an accomplishment that leaves fighters feeling mentally stimulated despite the physical fatigue. Separating these experiential components allows the individual to maintain a sense of forward momentum despite tiredness in the body. By publicly working to stay healthy and regularly engaging in agency-making practices, fighters fulfill cultural obligations and maintain a “purposeful engagement in the conflict between body and self” (Kaufman 2011:347), which has been identified as vital to the subjective wellness and longevity of individuals.

Due to the therapeutic nature of the program, many individuals find their ways to the gym through word of mouth and recommendations as a tool specifically to fight Parkinson’s. For this reason, many fighters enter the gym with some ambivalence over their belonging in such a space. Once in the door, the positive mood is contagious. Training at the gym becomes a moral-somatic process, which “allows cultural meanings to provide structure for attention, memory, affect, their neurobiological correlates, and ultimately experience” (Kleinman 1997:124). The gym creates conditions of possibility for self development and restructuring cognitive-affective processes that have the potential to increase a reserve of resilience, improve subjective well-being, and possibly even slow disease progression. Significantly, the attitude that an individual holds towards their aging experience has been strongly implicated in overall health outcomes and increased longevity (Wurm et al. 2007, Kiecolt-Glaser, et al. 2002a, Levy 2009). In her work on stereotype embodiment, Becca Levy (2012) has observed slower rates of age-related decline in performing

activities of daily living among individuals who have positive views towards aging. These individuals also had “better functional health over the course of the study and lived an average of 7.5 years longer than those with more negative self-perceptions of aging” (Levy 2009:332)¹⁹ Patterns between attitudes and health have been observed scientifically for decades. In fact, as a field, psychoneuroimmunology has been publishing research on how mental properties influence health outcomes since 1939 (Kiecolt-Glaser, et al. 2002b). I will further elaborate on the gym as an affordance for moral attunement through socio-somatic mechanisms later in this chapter (Synchrony and Zones of Empathic Resonance). First, I consider the processes of embodiment that offer re-adjustment of bodily sensibilities to acquire embodied capital and imbue lived-experience with an ethical subjectivity.

4.3 Ecology of the self

To holistically consider the mechanisms at play in the cultural patterning of sensations that influence behavior, health conditions, and lived-experience, it is essential to take a systems approach that accounts for interdisciplinary research. Accurately assessing questions of embodiment and biocultural influence requires a foundational acknowledgment that the human experience is embedded within a nested set of systems and subsystems that interact with one another to produce unique outcomes. Gregory Bateson proposed the term “ecology of the mind” to convey the multiple intersecting elements and overlapping structures that constitute the embedded embodied human and their lived-experience. In this section, I will follow his lead and consider how anthropological theories of embodiment intersect with cognitive neuroscientific

¹⁹ “...these health advantages remained after adjusting for baseline functional health and other relevant variables (Levy, Slade, & Kasl, 2002)” (Levy 2009: 332).

theories of grounded cognition and neuroplasticity to help us understand boxing as a cultural affordance that enables the accumulation of embodied capital and reconstructs a biographical narrative to incorporate a continuously disruptive companion called Parkinson's.

4.3.1 Grounded cognition and culturally-patterned modes of attention

In recent decades, anthropologists and interdisciplinary thinkers have advanced our appreciation and understanding of Merleau-Ponty's observation that perception occurs through cultural frameworks. Within phenomenology and the anthropology of experience, compelling arguments have been made for what Thomas Csordas (1993) terms "somatic modes of attention" that underlie and inform the texture of an individual's lived-experience and opportunities for potential behavior. Phenomenologically informed anthropologists have characterized the perception of experience as existing in two parts: pre-objective or the sensation/stimuli perceived, and objective or the sensation/stimuli interpreted through a personally and culturally-informed framework (Throop 2005). As the act of perception itself occurs according to culturally-informed understandings, there is no element of experience that is not in some way influenced by that individual's cultural development.

Anthropological research has demonstrated how an individual's cultural niche teaches the body to pay attention differently to various sensations and stimuli resulting in bioculturally distinct patterns of perception (Downey 2010, Csordas 2015). Psychological anthropologist Robert Levy (1973) noticed that patterns of cognition, sensations and emotional experience were dramatically different among his Tahitian research participants than his Western patients. He surmised that when a culture placed high importance on particular emotions, an individual would develop a more sophisticated discernment of the corresponding bodily feelings and better articulated behavioral options for expression. Bodily sensations are interpreted through cultural notions of moral behavior and experience, leaving feelings "amenable to considerable cultural

manipulation” (Levy 1973:324). Recent research has also found bodily sensations to be elicited differently depending on a person’s socio-cultural context and individual development (Rogoff 2003).

Ethical values are embodied in the individual such that the body is taught how to respond or behave in a given circumstance. In his work with Charismatic healers, Thomas Csordas (1988) demonstrated how extreme embodied experiences such as spirit possession (and the exorcism thereof) can be analyzed as culturally-patterned somatic modes of attention. Implications of morality make the mental interpretation of somatic experiences particularly significant to the subjectivity of the individual (Csordas 1988, Throop 2009). Among the Yapese of Micronesia, Throop observed the moral dynamics of interpreting chronic pain and the cultural capital available to those whose pain-inducing manual labor demonstrates an adherence to the moral duty to sacrifice physical comfort for the benefit of the community (Throop 2008). Clinical laboratory studies have agreed with ethnographic material documenting variations in somatization and perception in cross-cultural research (Nisbett and Miyamoto 2005, Ramstead, et al. 2016)

Grounded cognition is a paradigm of embodiment that emphasizes the role of the body in the process of cognition. It is gaining traction in multiple fields including anthropology. Rebecca Seligman (2018) has used grounded cognition to describe how ritual instills specific somatic modes of attention in her research on spirit possession among Candomblé practitioners of Brazil. She illustrates the use of food to associate feelings of satiety with a spiritual mode of being that allows this metaphor to cue a specific somatic mode of attention. Ritually pairing the feeling of satiety from feasting with a spiritual meaning primes the body to associate the spiritual with the fulfillment of basic needs. As individuals engage in an occupational domain (whether that is

spiritual medium or ballet dancer), they learn the necessary patterns of attention to properly perform in that world:

Through repeated experience with their social and material environments over time, bodies learn, accumulating embodied knowledge and developing what we could call ‘embodied trajectories’. That is, the physical and biological qualities developed by bodies through repeated experience represent a form embodied knowledge, which in turn shapes how new meanings are learned, and canalizes ongoing experience. [Seligman 2018: 399]

Analyzed from a lifespan perspective, embodied trajectories can help us understand individual health outcomes and behavioral choices. Longevity scholars have researched the common features of “Blue zones,” geographical areas with high numbers of healthy older adults and demonstrated that living within certain cultures can increase one’s chance of longevity and well-being in later life (Poulain, et al. 2021). Typically, a condition of benefiting from these biocultural niches has been a lifetime of accumulating embodied capital, healthy practices and community engagement.

By embodied capital, I am referring to “the physical and functional growth, strength, knowledge, and skills that are necessary for productive, reproductive and social success” (Hay, et al. 2021). Significantly, embodied capital does not refer exclusively to physical capabilities but perceptual and mental capabilities as well. Cameron Hay found that among individuals suffering from an autoimmune disorder, acquiring the cognitive skill to consciously avoid catastrophizing upon a dysphoric sensation effectively alters the trajectory of the body’s response and averts a feedback loop of suffering and inflammation. Kirmayer and Sartorius (2007) proposed a processual model of somatization that suggested sensations emerge through learned associations

that loop back upon one another reinforcing and re-igniting particular embodied experiences²⁰ which Rebecca Seligman (2018) has drawn upon to articulate the concept of “biolooping.” For Hay’s participants, catastrophizing leads to inflammation and pain, which encourages negative thoughts that keep the body responding to stress. Learning to break this loop gives a person the power to change the unfolding “interpretive arc” of the illness experience from a trajectory of suffering to an idiom of resilience that keeps them engaged in daily living (Hays, et al. 2021). Similarly, Lewis posits that one reason Tibetan refugees have demonstrated remarkable resilience despite personal and cultural devastation is due to the practice of mind-training that breaks the trauma loop and protects the self from chronic mental and physical distress (2013:316). The powers of interpretation are embodied and deeply influential to a person’s health outcomes.

The Candomblé practitioners of Seligman’s study acquire the embodied capital to enter trance and become mediums through biolooping processes during ritual pairings of food and numen with the embodied metaphor of satiety. Importantly, it is the metaphor of satiety that acts as the positive association to loop against the manifestation of this embodied experience. Metaphors guide the narrative structure (Kirmayer 2000). The neuronal networks activated during a mental simulation (such as memory or visualization) are nearly identical to the patterns that occur during an authentic experience (Barsalou 2008:635). This means the body is often able to trigger different states through mentalizing efforts. In appreciating the value of metaphor as an

²⁰ Based off of Ian Hacking’s (1996) notion of “looping” which described the feedback loop between self and cultural construction.

idiom of experience, it is relevant to recognize Michael Jackson's assertion that "Metaphor reveals, not the 'thisness of a that' but rather that 'this *is* that'" (1983:132).

Beyond the neurological, metaphors are deeply cultural. They "provide satisfying mappings onto already existing cultural understandings—that is, because elements and relations between elements in the source domain make a good match with elements and relations among them in the cultural mode" (Quinn 1991:65). Becker (1997) has observed how guiding metaphors may help to reinterpret a person's biographical narrative and serve a clarifying function. Metaphors are tools for working with experience and embodying cultural knowledge (Becker 1997:68). Resonating with a metaphor can shed light on previously hidden horizons of possibility and redefine modes of being in and engaging with the world: "Because metaphors frame and structure meaning, they may be highly significant in the process of attempting to reconstitute sense of self after a disruption" (Becker 1997:60). For Seligman's Candomblé religious healers, this is illustrated through the use of food to associate feelings of satiety with a spiritual mode of being that allows this metaphor to cue a specific somatic mode of attention.

While these are examples of cultural patterns addressing the embodied alterity of spirit possession, my research participants use the ritual of boxing training to admonish Parkinson's possession and reclaim "space" for themselves within their "embodied minds" (Scheper-Hughes and Lock 1987). Privileging certain sensory experiences and attending to clusters of sensations as meaningful generates "somatic modes of attention" (Csordas 1993). Parkinson's Fighters intentionally employ attentional techniques to enable protective factors through exercise and influence the path of their embodied trajectories to incorporate ethical modalities.

Fighters recognize the intense impact that the disease has on their family members and the hard work of their caregivers to keep them moving. Like all humans, they are deeply

impacted by their social engagements, and when Parkinson's is interrupting daily life activities, the fighter must grapple with embarrassing situations. One fighter kept his diagnosis hidden for years and would sit on his hands to hide his tremor during meetings. Others discussed the slippery slope of the "domino effect" in which biolooping exacerbates disabling symptoms.

During a female fighter ring-side chat, Mustang shared:

It's like you need to write a check, and all of a sudden, you know, your hand shakes like crazy. Or you're just waiting in line at the grocery store you know, you're standing there, you're fine. And all of a sudden, you know, you get the tremor, and you want it to stop. And the more you want it to stop, the worse it gets.

Moxie added: "then you're self-conscious because people are looking at you. And it just makes things worse... And when people are impatient, or people are looking at you it does... and, it's, it's really stressful." Being aware of the discomfort that others are feeling because of something that cannot be controlled not only produces a stress response in the body; it diminishes feelings of personhood and confidence in social engagement. Because experiences like this are typical of living with Parkinson's, participants sought new ways to engage personhood in social setting to re-affirm a moral sense of self. Training as a fighter at the gym, among others familiar with this predicament and non-judgmental about symptoms appearance, offers a valuable setting for this practice. Now that I've introduced the concepts of grounded cognition and the guiding metaphors, I will now explore the most important metaphor to my participants: the fighter.

4.3.2 Fighter metaphor

Metaphor enables enculturation by aligning embodied experience with meaning and offering a framework for perceiving "those experiences that reside on the fringes of our abilities to articulate, verbalize, and interpret" (Throop 2010:8). As Kirmayer observes, changing a metaphor that is foundational to the story of self can change the "dynamics of thought" and allow

individuals to rescue otherwise unhealthy cognitive patterns and psychological states (2000: 178 n10). The fight metaphor is a popular guiding narrative in the United States (Becker 1997: 126). My research participants were raised in environments that promoted independence, competition, and grit. They have life histories filled with vanquished challenges and moments of deep despair. Each of their particular circumstances and unique constellation of personal and cultural expectations, behaviors, and responses (or reinforcement) created unique embodied trajectories that encountered a similar disruption.

The fighter metaphor is instilled through training sessions that leave bodies exhausted and fighters with a sense of moral accomplishment. Physical fatigue can cue an internalization of the Coach's voice motivating the self not to give up and let the disease win. Moxie illustrated this by discussing a near-fall while hiking. As her body got tired, she felt her feet drag and catch on branches, throwing her off balance. As she began to waver, she heard Coach in her head: "Big steps!" he shouts during one of their warm-up exercises geared toward balanced walking. She felt her body respond, took a big step above the branches and maintained control through the rest of the hike. Moxie was not the only fighter to share such a story. When asked what it would look like for the disease to win, most fighters described a state of inactivity, withdrawal, and dependence.

Fighters are contesting the meta-narrative of decline that overarches both aging and Parkinson's Disease. As Kaufman notes, "the impaired and restricted body, perhaps in American society particularly, significantly threatens the conception of an intact and autonomous self" (2011:343). By generating new ways of engaging with their moral selves, fighters reclaim agency and shift the illness narrative into one of resilience and wellbeing. Staying active and generative in the face of progressive decline acts as an idiom of resilience by demonstrating their

dissatisfaction with the public perception of being powerless or incapable. Fighters are hopeful that engaging in idioms of resilience educates individuals about Parkinson's while impressing upon them a maintained integrity of self and moral personhood.

Even after the disease progresses such that a fighter requires hands-on assistance with activities of daily living, the refusal to stop engaging in health-related activities (such as boxing) re-affirms their moral convictions and social responsibility. Similar to other explanatory models of misfortune such as sent-spirit narratives in Haiti, boxing training sessions "not only enable emotion processing but also enable the avoidance of other, potentially more harmful emotions" (Kaiser 2019:383). Boxing is a performed resistance to embodying "the sick role" or resigning control over the body's health. The Parkinson's patient becomes the Parkinson's fighter. They are not a patient, a passive recipient of care; rather they are actively engaged in the ethical occupation of self care. Metaphor makes suffering more palatable by allowing the individual to define their own parameters of experience and acquire ownership over their situation.

4.3.3 Parkinson's as a metaphor

Ownership and curation of a person's own narrative can act as an idiom of resilience to promote moral agency and ego-integrity. My participants re-define the progressive degeneration narrative into a battle for time, to delay that which is inevitable to us all. Adapting a unifying perspective over exceptionalism allows fighters to experience Parkinson's as another variant of the critical human condition rather than a type of personal or spiritual attack. There is a deep-seated recognition that life is a challenge for everybody regardless of how it appears from the outside. During one of our group conversations, one fighter reflected: "Everybody out there goes through something that terrifies them like Parkinson's terrifies us and that's just part of being human, being mortal." He was met with agreement and a second fighter offered, "ours just has a name." It is not uncommon to hear gratitude for what the illness is *not*: 'At least it's not cancer,'

‘at least it’s not ALS,’ ‘at least it wasn’t an abusive parent in childhood.’ I was surprised to hear childhood experiences included in comparisons. There are two elements to this perspective: Parkinson’s as unifying and gratitude for their positionality on the spectrum of potential suffering. The gratitude is extended to the opportunities that Parkinson’s has opened through their engagement with boxing. Mustang reflected, “if we didn’t have Parkinson’s, we wouldn’t have boxing.” This resonated so strongly with Challenger that she encouraged Mustang to repeat the line.

Parkinson’s is not appreciated or welcomed by any stretch of the imagination; instead it is transformed into its own metaphor for human struggle. A similar sentiment is expressed by Michael J. Fox, who discusses using Parkinson’s as a technology of character study in his acting work: “Putting the emphasis on my character’s vulnerabilities and not my own, Parkinson’s could in fact disappear, and be morphed into whatever my character was living with... I *can* play anyone, as long as they have Parkinson’s. And as I was discovering, *everyone has Parkinson’s*” (Fox 2020:24-25). While the fighter metaphor guides strategies of coping with physical suffering, transforming Parkinson’s itself into a metaphor for the critical human condition provides psychologically protective and spiritually connective qualities. It can also boost compassion and a deeper awareness of the complexities underlying every individual’s surface appearance. As Sara Lewis noted: “compassion is not merely an ethical value, but it is used as a practice of technology to work on the self” (2018:346).

The transformation of Parkinson’s as a personal attack to a metaphor for the critical human experience is evocative of Lewis’s work among Tibetan refugees in Dharamsala, India, who express the value of personal suffering for nurturing compassion for others who are suffering (2018:343) as a culturally-appropriate idiom to guide rehabilitation. This perspective

allows refugees to dwell in a sense of connection and relationality as opposed to isolated or self-indulgent. Fighters who felt Parkinson's could be viewed as an extension of any life-altering challenge were able to connect to a unifying compassion that was healing and transformative to their illness narrative.

According to participants, adapting well to life with Parkinson's is aided tremendously by accepting the human connection that this struggle offers, as opposed to experiencing it as distancing. Denial and withdrawal lead to increased stress and worsened symptom experience. One fighter compared illness denial to being in the ocean, but instead of diving into a wave that's coming at you, jumping up and letting it hit you in the face. For them, getting comfortable with being uncomfortable is essential to surfing the vicissitudes of good days and bad with chronic illness.

As alluded to earlier, there are also certain physical symptoms such as swaying or head bobbing that are not noticed by the individual until pointed out by a friend or family member. This can be a humbling experience, and multiple fighters express a determination to notice this behavior and intervene whenever possible. One of the hallmark signs that immediately tips off the neurologist to Parkinson's is walking without swaying the arms. This can interfere with balance and momentum, which can increase chances of a fall. Fighters actively work to remember making movements that many individuals do not realize that they are doing. Instilling habitual behavioral responses that were previously embodied is a uniquely complicated challenge that threatens the subjective experience of personhood as well as social acceptance. Fighters have commented on how relearning skills typically follows a similar trajectory as learning them, and a person may notice familiar signposts of physical growth or

accomplishment. It can become increasingly challenging to reach certain stages which have the potential to inspire judgment and frustration from the self or others.

In this section, I have discussed how metaphor is used as a technology of the self to align experience to an ethical subjectivity supported by culturally dominant ideals, while simultaneously connecting the individual to other humans through the critical human experience of suffering. Now that the internalization of metaphor has been introduced, I will turn to discuss the effects of skill acquisition on the health and subjectivity of the Parkinson's fighter.

4.4 Ecology of the Parkinson's Fighter

In Gregory Bateson's discussion of an ecology of the mind, he posits multiple layers of developmental influence that occur during learning and skill acquisition. Bateson observes that "habits" of thought and the way an individual perceives abstract concepts are "in some sense, by-products of the learning process" (1987[1972]:171). As a person learns a skill, they are learning particular apperceptive habits in parallel with acquiring the skill itself. They are developing an embodied trajectory that alters perceptual frames and cognitive patterns. This has the effect of "learning to learn" and provides an entry point for cultural influence. The more frequently a dancer learns a new routine, the quicker and more effective that process becomes. In the context of boxers, they are developing their skills of fighting and resisting.

A Batesonian ecology of mind includes a network of interactions and connected features within individuals that are influenced by the characteristics of one another. Through meta-communicative frameworks such as play and ritual, individuals attain new narrative structures to safely experiment with the interpretation of various stimuli. For example, two puppies playing will not perceive a nip from their mate as an aggressive signal eliciting a fear response; rather it will provide them an opportunity to learn to engage in a simulation of fighting, develop a

connection with a member of the pack and exercise the body. “Mood-signs” operate as a meta-communicative device framing the perception of events and guiding appropriate behavior (Bateson 1970:195). Misperceiving appropriate meta-communicative signals, applying inaccurate frameworks or falling into particular cognitive habits may be distressing. Learning different patterns of psychological framing is not only descriptive of a psychotherapist’s role according to Bateson, but it is foundational to many of the current popular evidence-based practices in mental health such as cognitive behavioral therapy (Hayes and Hoffman 2017). These interventions are often linguistically-based and reliant on dialogue, but we can see the value of non-linguistic metacommunication for promoting healing as well. For people who have lived through trauma, embodied practices like yoga may be able to unlock a tremendous amount of emotion, allowing the body to re-process certain stimuli (Forrest 2011:254; van der Kolk 2014:275-276).

The primary system of embodied grounded cognition that relies on unconscious processes of proprioception and motor control occasionally fails to communicate with the Parkinson’s fighters’ bodies. This is when the body falters, falls and/or freezes, potentially putting the individual in serious danger. The secondary fighter cognition plays in their head, and Coach’s instruction can be heard, affording the person another chance to regain bodily control. I propose that the repeated practice of training as a boxer “acquires the power of responding with a certain type of solution to a certain form of situation” (Merleau-Ponty 2013[1945]:178), a secondary body schema through which to engage with the world.

Boxing teaches people to “punctuate” (Bateson 1972) reality with opportunities for innovation and self-expression. The highest moral in boxing is to stay in the fight after all. Using cultural scripts in novel manners creates an “adaptation to the *context*” (1972:300) as Bateson

would say that inspires deeper developmental changes and opens horizons of potentiality and further growth. Wacquant observed, “By entering an occupation that hinges on the willful undertaking of serious chances; boxers decisively realign the structure and texture of their entire existence -its temporal flow, its cognitive and sentient profile, its psychological and social complexion - in ways that put them in a unique position to assert their agency” (1995:510). For a person with a condition that directly impacts one’s “entire existence” defined in Wacquant’s terms, boxing provides an ideal resource for learning to learn to realign the self. The structure of boxing training is such that a person embodies new habits of attention and energy direction in a safe thought high-stakes environment that requires an immediacy of action. Anecdotally, concentrating on physical experience during intentionally strenuous activities such as boxing training seems to improve the likelihood that an individual will be able to call upon that embodied knowledge during spontaneous challenges (for example, Moxie hearing Coach’s voice and successfully lifting her knees high enough to avoid branches and hike safely). Parkinson’s boxers may not be taking the “serious chances” involved in defending against a prizefighter, but the risks from losing bodily control (such as falling) are severe. Unlike prizefighters, my participants did not willfully choose to develop Parkinson’s, but the decision to adopt a fighter identity affords an existential realignment that strengthens and expands the realm of inner agency.

Boxing thus offers itself as a cultural affordance that allows the cognitive system to adapt to fluctuating levels of bodily control. As Ramstead et al. (2016:4) observe, new cultural affordances, or the ability to engage with the world in specific and meaningful ways can be gained through various forms of learning. These affordances shape the field of available actions

and thus expand or constrict agentic potential. This demonstrates the transformative properties of idioms of resilience that generate useful cultural affordances for an individual.

Cultural affordances offer individual actors a practice with which to resist certain types of ambiguity and “entropic disintegration” (Ramstead et al. 2016: 8). In considering how such embodied cognitive processes are habituated into usefulness, Ramstead et al. hypothesize “feedback loops mediating shared attention and shared intentionality are the principal mechanism whereby cultural (especially conventional) affordances are acquired” (2016:7). Again, we see how the notion of “looping” is foundational to embodied experience and the development of cultural knowledge. Through “conventional affordances,” fighters access possibilities for engagement with the world through practices that reflect the local moral context and behavioral expectations of the group. Influential to this process is the background of synchronous experience.

4.4.1 Parallel plasticity

Synchrony organizes neuroplasticity. Neuroscientific research has validated Bateson’s observation that the development of one skill can directly influence the development of another without overtly addressing these parallel traits. This “binding problem” (LeDoux 2002:310) is one of the mechanisms occurring in individuals who are haunted by post-traumatic stress disorder and find their bodies triggered by stimuli into experiencing the same physical and psychological state of panic that occurred in an entirely separate context and time. This chunking process can also be beneficial. Neuroplasticity is a recognized corner-person to Parkinson’s fighters. To the fighters, who literally discuss plasticity as a part of their toolbox, it means using what you have while you have it to keep ownership of your body for longer. In discussing plasticity, one fighter said: “That's how your brain works. It will reroute. So I figured out I was

just going to reroute Parkinson's." Chunking physical exhaustion and muscular fatigue with vibrance and morality leads to feelings of self-actualization and well-being rather than defeat. Professional (and many amateur) boxers are at their peak levels of physical fitness. They have mastered their bodies and trained their muscles to do exactly as they are told. Muscle coordination is an especially enviable trait in the Parkinson's community. Regularly getting into the headspace of a boxer, the *sense of the sport* as Bourdieu called it, encourages the ease with which embodied cognitions will be drawn upon according to participant stories. This suggests the cultivation of durable dispositions have been successful.

As mentioned, research in grounded cognition supports Jackson's claims of "this is that" and demonstrates that my research participants are not symbolic fighters, they are literal fighters simulating the physical experience of a bout. Using the fight metaphor to bind the feelings of determination and success with the feelings of physical exhaustion creates the opportunity for what neuroscientists call "parallel plasticity." As boxing skills are acquired, determination grows. I propose that the association with fatigue allows fighters to call back this fighting spirit when confronted with pain and exhaustion from Parkinson's outside the gym. Re-assigning fatigue to a moral meaning and attending to it as a sense of accomplishment alters the perception of the experience and the trajectory of behavior and social or health-related engagement. Thus boxing is incorporated into an individual's ethos.

At the end of the session, their bodies hurt, but there is a tremendous sense of success and accomplishment. Sometimes there are temporarily renewed sensory capabilities (such as Moxie being able to smell the restaurant across the street), and often there is a boost of mental energy to socialize or work on a passion project. The fatigue and sore muscles are disassociated from indications of illness or defeat and paired with success and moral personhood. Most fighters are

not new to this association of fatigued muscles with accomplishment, but when another experience such as Parkinson's has disempowered the connection, a repeated renewal of this association is valuable. By working on multiple levels within the ecology of the mind simultaneously, fighters are able to bring the embodied wisdom from the gym with them to other parts of their lives. One participant said that the sound of Coach's voice immediately brings back the feeling of determination that she has when she is in the flow of a good workout. Another shared "[the training] comes to mind when I notice that I'm shuffling or not walking properly, I think: Well, let me go back to my monster steps and let me get that heel-toe thing going and it works for me."

If the fighters had learned to learn, it would be reasonable to see evidence of this when they rejoin in-person classes. Returning fighters should have an easier time of picking up the boxing routines than new fighters, and this benefit should at least slightly extend to those members who joined during the pandemic lockdown and had only exercised with the group online. The first week back, there were strict regulations about how many people would be allowed in a class, with only six fighters per session and advanced sign-ups required. Coach was not sure how much work it would be to re-acquaint people with the mechanics of the gym. Moxie was one of the first to sign up for in-person training. She missed hitting the bag and sparring with the trainers. Since adding volunteers to the mix was not advisable at the time, I headed over to Moxie's after class to hear how it went.

I sat in the front yard with Moxie and her sister while eating bagels and discussing some of the recent changes. Her first class was split evenly between three returning fighters who had been following the classes on zoom (one of who had joined during the lockdown), and three new fighters who had never attended a class. I was surprised that there would be three new members

join on the first day of in-person instruction, but as it turned out, Coach had been developing quite the reputation among the medical community during the lockdown.²¹ Coach hoped the others would get back into the swing of things without as much concentrated effort as required to initially introduce someone to the lay of the gym, and he let the returning fighters know this. I asked if his assessment was accurate or if it took some time to get back into the swing of things. Moxie was excited to report that it felt just like old times. She was proud of the fact that she knew what she was doing in her boxing gloves and expressed joy over being able to help bring the experience to the new gym members. As in Magma's story (chapter two), living loudly and proudly with Parkinson's was seen as a form of activism for multiple women who strove to increase solidarity and support within the community. If others with Parkinson's saw them thriving, they might develop courage to participate in their own health and social events. And if others without Parkinson's were to realize how much life still exists despite a motor disorder, it might educate them in their treatment of others and understanding of the disease. That is certainly the hope. At the crux of this shared education is an empathic awareness that must be re-developed within the context of the illness. I will now turn to how the gym cultivates a sense of belonging and empathic resonance that affords this type of self-growth and transformation.

4.4.2 Synchrony and zones of empathic resonance

What stood out as a fundamental condition of possibility for enculturation is training or learning in a zone of empathic resonance. Training or learning a skill unrelated to Parkinson's with other people who have Parkinson's accomplishes this. As opposed to traditional support

²¹ In fact, in the first month back in the gym, at least four doctors with Parkinson's joined the gym after hearing about the program from colleagues.

groups²², the emphasis at the gym is on learning to box and using your body well. The coach addresses the specific issues that people with Parkinson's face with their bodies such as balance and dexterity, but there is no pity, no sorrow and the focus is not on the illness experience, just skill acquisition and admiration for one another. The fighters find great inspiration from one another and often count the more advanced (disease wise) fighters among their role models and personal heroes. One of the major features of Parkinson's is displaying an outward appearance or cues that do not accurately reflect the person's internal feelings and states. It is difficult for caregivers and friends to empathize with the relatively harmless but strange symptoms. After a while, this dissonance and the symptoms themselves either become humorous or heartbreaking. For this reason, I suspect that family and caretakers are not necessarily well positioned for zones of empathic resonance. As sympathetic as many of them surely are, their particular relationships and shared interests may be obstructive.

Whether it brings suffering or joy, humans need to feel a sense of belonging with others. In many instances, synchronous behaviors can create that sense of belonging. Finding opportunities to be in sync with others can be difficult when a person's temporal framework is impaired. Training as a boxer along with other Parkinson's fighters allows for the opportunity to do this. Synchronous experience not only connects us with humankind affording a sense of belonging and unity, but it enables enhanced learning and memory (Davidesco et al. 2019, Pan et al. 2020). The gym provides a self-contained space to practice a new set of coordinated behaviors within a social context. After leaving the gym, fighters return to daily life, but the

²² Many fighters find value in the support groups. However, several of the fighters tried to attend support groups but experienced what they felt was an uncomfortable level of pity in these interactions and chose not to return. These fighters felt the groups provided a more myopic approach to disease, and this did not offer the therapeutic value that they were able to find in socializing with fellow fighters.

parallel plasticity, social bonding and endorphin releases that occurred during trials of physical determination support activities and mood throughout the day.

While the fighters' movements are not in perfect synchronization, they are mostly engaging in the same actions. The exercise stations provide some room for personalization depending on the individual's capabilities and needs, but they are relatively equitable in style and effort. For all intents and purposes, they are all learning the same moves and following the same routine. Some fighters rely on being able to follow along with others as five exercise stations with different routines is a lot to remember after only hearing the instructions once. There is always someone happy to help. From my eyes, fighters seem to have a sense of how to assist one another and when it is appropriate. Regardless of level of impairment or time at the gym, all fighters are equal in their personhood.

Living with Parkinson's involves frequent interactions with a healthcare system that sees the person as a patient and expects a marked decline in their health. The ability to engage in health-related behaviors while maintaining a sense of authorship over one's own narrative is therefore a particularly meaningful assertion of personhood to my participants. As Cohen notes, "In addressing their social commitments, including their membership of organizations, individuals may be regarded as speaking in the active voice, rather than as having behaviour determined by structures which are imposed on them" (1994:94). They are not patients; they are active fighters. According to participants, having others who can relate to this transformation and offer support provides a feeling of protection against the more dehumanizing aspects of healthcare treatment.

Boxing is not traditionally a team sport, but this program offers a strong sense of community and support nonetheless. The gym feels like a team, and Coach works hard to

cultivate that ethos. As mentioned previously (chapter three), each fighter has a boxing nickname, and once a year, new tee-shirts are made with boxing names on the back. There are also literal teams that are organized for community events like an annual 5k to raise awareness and funds for the Parkinson's Association of San Diego to which members wear their tee-shirts proudly. This is particularly beneficial, as longevity researchers have observed a common practice among individuals who maintain healthy aging is regular social engagements and support (Reichstadt, et al. 2007, Jeste, et al. 2010, Douglas, et al. 2016). For people who suffer the vicissitudes of chronic disease, routine meetings can be difficult due to health fluctuations. This is occasionally complicated by individual pride and the reluctance to be social when unable to appear healthy. Even the small behavioral choices like what to order for lunch become a challenge when considering current motor abilities and the potential to initiate a biolooping of symptom severity as discussed previously. The group of fighters create a space where they can socialize without the fear of being watched or judged by others. During one group lunch, Dynamite reflected on the joy of being able to order a salad. He wouldn't have done so with his non-Parkinson's friends.

Beyond the emotional benefits, zones of empathic resonance afford opportunities for social experience and synchronous behaviors that literally boost the body's endorphin production and release (Launay, et al. 2016). This is especially valuable to Parkinson's fighters, as the endorphin system provides immune support and benefits health outcomes in multiple ways, including the improved ability to fight viruses (Williamson, et al. 1988) and cancer-causing pathogens (Kikuchi, et al. 1989, Sarkar and Zhang 2013), as well as improving pain, stress, and mood (Shrihari 2018, Jain et al., 2019, Ali et al. 2021). The boxing gym incorporates social bonding and exercise, both of which provide an endorphin release (Launay, et al. 2016), giving

multidimensional support to the individual's health and wellness. Research in evolutionary neuro-anthropology has shown that synchronous social experiences themselves release endorphins, likely as an adaptive mechanism that allows humans to bond in larger numbers without the excessive time spent grooming that is seen in other primate species (Launay, et al, 2016). Lakens and Stel (2011) demonstrate that coordinated movement often occurs among individuals on an unconscious level to facilitate social interactions. Further, that synchronous experience builds rapport and communicates messages of group membership (Lakens and Stel 2011:4). For people with Parkinson's, coordinating their body movement in rhythm with others presents a fundamental challenge. The body may struggle to meta-communicate messages of membership at quite the same level, but at the gym their efforts are understood. Launay, et al posit that "social behaviours that involve synchronized movements (e.g. sport, music, ritual) can be understood as technologies developed to exploit existing neurobiological and psychological mechanisms which are important in the maintenance of social bonds" (2016:122). Training as a boxer with others experiencing similar bodily dissonance offers a valuable dosage of belonging and meaningful psychological engagement among others who can understand the subtleties of sharing a body with Parkinson's.

The gym as a zone of empathic resonance provides fighters the opportunity to discuss potentially embarrassing symptoms that carry marks of stigma among others. In my observations, it seemed that certain symptoms were considered stronger indicators of decline by practitioners and family members than by the fighters themselves. This was especially true of the experience of hallucinating. Hallucinations are progressive if untreated and can lead to increased frequency and amount, in addition to more serious developments such as delusions (Goetz, et al 2006). For this reason, physicians tend to alter medications when hallucinations appear to

discourage this trajectory, which has been relatively successful (Sanchez-Ramos, et al 1996). Typically, the experience of “benign hallucinations” was subjectively far from a full break with reality. Many of my research participants were fully aware of their visions as funny little projections of dysregulated dopamine in the brain and had no delusions about their veracity. Visual and auditory Parkinson’s hallucinations are more similar to those that occur among visually-impaired (Barnes and David 2001) and hearing-impaired (Factor and Molho 2004) individuals than those occurring among people with schizophrenia. They are typically non-threatening and can even be relatively pleasant at times. One participant enjoyed sitting with a Siberian tiger, while another would see her loving daughter or granddaughter lying in bed next to her upon waking. Talk of hallucinations, however, only causes concern in caretakers, which is highly understandable but obstructs a person’s ability to laugh things off or even simply accept them as part of the new normal. The gym became a space to share and laugh about these scarier sounding stories and essentially justify their experiences as still human.

Hallucinations were a popular topic of conversation for my participants despite me never explicitly situating a conversation around them. This may be due to the difficulty in connecting around this shared experience. Fénelon et al. (2000) observed a higher depression score among hallucinators compared to their non-hallucinating counterparts. As mentioned, fighters expressed a sense that this experience may present a challenge for loved ones’ empathy and concern over the fears that it may engender among caretakers and friends. Interestingly, hallucinations have been cited as one of the main causes of nursing home placement for people with Parkinson’s (Salawu, et al 2010:128). There were rarely other people with whom they could talk about these symptoms without the worry that their interlocutor would begin to look at them differently with

that knowledge. The group became a space to connect and laugh about these experiences as well as admit to increased frequency without fear of losing agency or social capital.

As hallucinations progress and become more serious, the distinctions between hallucination and reality begin to blur more easily (Goetz, et al. 2005:715). Participants conveyed that the most concerning thing about moments of reality confusion was the potential impact that they could have on the spouse. Multiple fighters expressed fear that they may harm their spouse without realizing their actions. Fighters would describe hallucinations that occurred in between states of sleeping and waking that led to some confusion from me and some of the other fighters who had never shared the experience. To us, it sounded like light dreaming just before waking, but the fighters insisted that there was a phenomenological distinction.²³ The night time hallucinations were far more unsettling than the rather innocuous figures of people or animals that appeared during the day. Scorpion, a male fighter, described hallucinating a struggle with a home invader, only to be awoken by his wife to find himself pulling on his own arms and unable to let go. Upon finally releasing his arms, the force of his struggle sent his body flying backwards. This process of regaining control was as frightening as the struggle itself on a much deeper level. Scorpion replayed the event with a different ending. What if he'd flown into his wife and hurt her instead of their bedroom chair? He pondered aloud. What if he had been grabbing her arms instead of his own and she had been the one to walk away with bruises? The prospect of causing harm to a loved one due to lack of physical control violates multiple North American ethical tropes including self-discipline, rational behavior and expectations of care (Kaufman 2011). Another fighter shared having heard auditory hallucinations telling him that he

²³ The experiences of altered states and intricacies thereof are fertile areas for psychological anthropology research. I hope to investigate further in the future but a deep dive into the topic lies beyond the bounds of this dissertation.

was in the wrong house and he needed to pack up and leave. A second fighter said that he had another friend with Parkinson's who had shared a nearly identical hallucination with him previously. It struck me that these experiences essentially involved confusion over ownership and belonging. As Parkinson's invaded their bodies, their minds projected an internal struggle through the metaphor of home invasion.

4.5 Conclusion

In this chapter, I have illustrated a modality of successful aging through the process of self-transformation that occurs among people with Parkinson's who take on the guiding metaphor of fighter. Theories in grounded cognition elucidate how the fighter metaphor can be used as a narrative to perpetuate ego-continuity and acquire new modes of accessing an embodied ethical subjectivity that promotes characteristics of resilience and healthy aging among the "survivor" phenotype of successful agers who are able to "preserve well-being amid physical functional losses" (Depp and Jeste 2006:18).

The primary system of embodied grounded cognition that relies on unconscious processes of proprioception and motor control occasionally fails to communicate with the body in Parkinson's. This is when the person falters, falls and/or freezes, potentially putting the individual in serious danger. The secondary fighter cognition plays in their mind, and Coach's instruction can be heard affording the person another chance to regain bodily control. I propose that the repeated practice of training as a boxer "acquires the power of responding with a certain type of solution to a certain form of situation" (Merleau-Ponty 2012[1945]:178), a secondary body schema through which to engage with the world.

Actively engaging in the "conflict between body and self" (Kaufman 2011:347) engenders experiences of agency and morality that are beneficial to subjective well-being and

fulfilling expectations of behavior. The repeated embodied learning that occurs during boxing training sessions activates an ethos of determination and gratitude while binding this phenomenological profile to feelings of exhausted physical effort, fatigued muscles, accomplishment and tenacity. Physical exercise in parallel with the empathic resonance that occurs between fighters at the gym generates positive protective factors including belonging, immune support, and overall improvement in quality of life (Launay, et al. 2016, Larson, et al. 2021).

I have described the therapeutic benefits of socializing and exercising in a zone of empathic resonance particularly for individuals with fringe experiences of aging. Fellow Parkinson's fighters encourage the activation of characteristics that match cultural and personal conceptualizations of value and morality while engaging in group socializing that has been demonstrated to counteract brain aging (Colonnello, et al. 2017). Conforming to group behaviors and expectations produces specific changes in the brain and strengthens certain processes of the self (Stallen, et al. 2013). In this case, it is the ethical and resilient elements of the self that are bolstered by the community of determined fighters.

Parkinson's presents a challenge to maintaining a coordinated temporal rhythm with others. Behaving in synchrony or with expected patterned reciprocity is one of the subtle yet pervasive encounters that normalize a person throughout the day. Fighters are no longer asked to pass the salt, pour the coffee, toss the keys, or even answer questions about their own bodies. This chapter has demonstrated how the gym creates a zone of empathic resonance that facilitates the continuous process of self-making necessary for individuals living with chronic disorders, particularly those that progressively disrupt familiar embodied experiences, motor control and social engagement. Sparring in the ring and training exercises outside of the ring offer

opportunities for harmony and successful reciprocal interactions. They offer validation of personhood.

Chapter 5 The Lesson

5.1 Introduction

Throughout my fieldwork, people would ask me why I was studying Parkinson's Disease. Their expectation was often that I had a relative with the illness or other personal engagement to the experience. This was not the reason. While my own neurological challenges with a migraine disorder certainly played a role in my interest in self-experience and shaped certain questions around illness management, my curiosity about the disease began before I was diagnosed with my own. I framed my answer differently depending on the person's familiarity to the disease. When I was speaking with a member of the Parkinson's community, I explained that I had been drawn in by the unique challenges that the disease posed to a person's self- their ability to communicate thoughts and feelings, eat and walk easily, and essentially occupy a familiar body. This would often be followed by an immediate recognition in the face of my interlocutor and meaningful nodding. I was nervous at first to make this claim when it was in actuality an assumption that I'd drawn from reading about Parkinson's, so it was relieving to see the immediate understanding of why this *was* in fact an interesting puzzle for a social scientist. My participants were well-educated individuals who had not lived unexamined lives, so to speak. They had spent time reflecting on their experiences without overt encouragement, but my questions were welcome prompts that allowed for a deeper exploration into how their lives had been affected by this disease. My assumption was correct: Parkinson's presented unique challenges to processes of the self. However, I was not prepared for the amount of resilience and inspiration that would be apparent in my participants' responses to this existential crisis, nor was I expecting the level of contagion that their determination spread.

I have had to leave a good amount of fascinating information out of this dissertation. Even more, I have learned a good amount of deeply valuable knowledge that will always escape articulation but has profoundly impacted my own understanding of life and aging on a molecular level. As lovely as doctorate degrees are, this embodied understanding is perhaps the most valuable tool that I could have gained from this research. For me, it was my own experience working with the fighters that drove home a fundamental truth of humanity- the need for belonging and the immense mental and physical health benefits that are derived from these community engagements.

5.2 Summary of dissertation

This is an ethnography of survivors who have learned to thrive in spite of Parkinson's Disease. I began with a description of the phenomenological disruptions that occur as the disease invades a person's body and the identity recalibration that it required. I then explored the introduction of the gym to the individual's budding identity as a Parkinson's fighter and the social transformation that occurred when joining the group. From there, I considered how these social practices and acquisition of boxing skills were self-transformative and impacted the "ecology of the self" for fighters who were able to internally resonate with the ethos of resilience and determination in the gym.

Kaufman asserts, "Phenomenological studies of existential responses to illness are necessary to understand cultural sources of unmet expectations resulting from chronic conditions" (2011:351). I have attempted to illustrate how boxing is used as a cultural resource by older adults who must adapt to life punctuated by healthcare institutions that are incapable of fulfilling the unique needs of a person with Parkinson's. This was particularly true of women who are a minority in the Parkinson's community and struggled to receive the appropriate care.

In chapter two, I illustrated the gendered experience of women receiving a diagnosis for Parkinson's and the challenges of legitimation that they faced. Additionally, lack of visibility in the community created awkward tension for some of the female fighters who did not want to be the only woman exercising in a group of men. A sense of gender solidarity was beneficial to generating a feeling of belonging while coping with the loss of motor control and the changing access to regular social roles that had previously been a source of interaction and self-validation (e.g. full work days, playing music with friends, mirroring facial expressions). I also demonstrated the recourses taken by Parkinson's fighters who were not receiving appropriate care. When mistreatment was offensive enough, like was the case for Moxie, immediately terminating that clinical relationship was an effective method of obtaining proper treatment. The confrontational manner with which she communicated her need (a referral for a movement disorder specialist who would treat her with dignity) to the diagnosing doctor likely altered his future behavior. This was illustrated by her overhearing multiple new patients at the movement disorder clinic report being referred there by his office. She felt pride for being able to make a difference in the way other patients were treated and made it a regular practice to reach out to others with Parkinson's to share knowledge and self-advocacy support. As the daughter of a doctor and a confident woman in her own right, Moxie was aware of the fact that her ability to navigate healthcare and deal with difficult people was above average. She felt for others who did not have this skill and was frustrated by the necessity of confrontation when seeking care. Like other women in the study, sharing her stories and encouraging others to self-advocate was her attempt to empower others with this social capital.

Chapter three introduced the gym as a local moral world in which fighters were able to exercise not only their bodies but ownership over their biographical narrative while developing

supportive social relationships. I explored the technologies of unity that engendered a sense of community at the gym and encouraged sustained participation. Importantly, the relationships that developed between fighters and with Coach further validated feelings of personhood and motivated the continuation of training and cultivation of resilience.

The gym provides a self-contained space to practice a new set of behaviors with desirable problems for the brain to solve within a context that affords a resilient sense of self. There are few cultural affordances with which to disclose the self spiritually as well as physically. These become rarer when one's body requires specialist knowledge to train safely. The boxing ring provides an opportunity for a person to push their body and self-knowledge to the limits of their understanding. It enables a fighter to explore the boundaries of their physical and emotional experiences in a safe space. Ethics of boxing prohibit resignation and demand a level of self-control and responsibility that parallel the dominant cultural ethos of my participants (Becker 1997). This meant that practicing boxing was effectively a demonstration of their cultural value. The boxing gym not only brings elements of mental and physical growth into the realm of possibilities for people with Parkinson's; it creates a space to perform moral personhood. Research participants used the ritual of training as a boxer to admonish Parkinson's possession and reclaim "space" for themselves within their "embodied minds" (Scheper-Hughes and Lock 1986) and generate "inner agency" (Lewis 2018).

In chapter four, I demonstrated how the fighter metaphor is embodied through processes of grounded cognition including neuroplasticity, biolooping, and synchronous experience. The gym creates a zone of empathic resonance that trains the body as a boxer and validates marginal self-experiences as human and moral. Not only does boxing protect the body from Parkinson's progression through motor training and releasing protective endorphins; the gym environment

triples the impact by addressing the social and moral personhood affected by Parkinson's. Synchronous experience with other fighters normalizes an otherwise atypical somatosensory experience. This demonstrates how important it is to human survival and quality of life for a person to remain socially engaged and, beyond this, the value of being social among others whose empathic abilities resonate with our embodied experiences. The fighter metaphor resonates with cultural ideals of self-determination and toughness, facilitating the acquisition of - and imbuing the body schema with - an ethical subjectivity. Fighting as a guiding metaphor emphasizes the process of disappointment, pain and rehabilitation while valorizing the virtues necessary to thrive along this temporal cycle of experience. For a person whose biographical narrative was disrupted by Parkinson's, this embodied orientation to the world configures a structure of understanding that emphasizes the positive of what one is accomplishing over the negative of how one is degenerating. It re-focuses attention on the self and away from the disease. Internally, one is able to reconnect to a valued sense of self and bring continuity back to their narrative. Additionally, friends and family have a topic of wellness to ask the individual about instead of Parkinson's to demonstrate their care. Fighting is both an inter and intrapersonal idiom of resilience that can be used by interlocutors to demonstrate concerns for wellness without mentioning a salient aspect of their bodies that will never disappear.

5.3 Limitations to study

This work would have benefited from quantitative data about attitudes towards aging and subjective successful aging assessments. I had initially intended to collect this information, but during the COVID-19 lockdown, it became impossible to ask the participants to divorce their experience of lockdown disruption from their daily Parkinson's life. This work could have benefitted from more survey and quantitative data collection about progression rates and

symptoms over time. This would have required working directly with participants' medical care teams and accessing private information, which exceeded the bounds of my research approval. As my focus was more related to the experience of the self and communicating identity, I did not pursue data collection that involved health records. This could be added to ethnographic data however, to derive complementary more insights.

Also due to the focus of this work being on female fighters, I did not conduct too many personal interviews with the male participants, which could have generated a deeper comparison of the gendered experience. This created a situation in which I was slightly less likely to follow up on comments made by male fighters during ring-side chats that may have further elucidated the phenomenological condition. I regret the lack of time and attention spent on care partners in this research, particularly as it appears to be a frequently under-supported and overlooked group of dedicated and loving individuals. I had intended on interviewing members of this group and holding a couple of situated-conversations with family and caretakers but was ultimately unable to find the bandwidth to accomplish this task within the given time. In the future, I would like to pursue the topic of changing relationships and further develop an appreciation of the effects of loving and living with someone who is undertaking the “project of ontological transcendence” (Wacquant 1995:509) that is Parkinson's boxing.

A significant amount of this research was conducted over zoom video conference. I did not feel as inhibited by this distance as I feared I might. I was, however, limited in my ability to visit other Parkinson's-focused boxing gyms to compare with the experiences of my fighters. With the COVID-19 pandemic overlapping with a significant amount of the study and the high risk of virus complications for the population in question, gyms were not meeting in person. The loyalty developed between Coach and fighters was certainly instrumental in the success of the

group meeting virtually and maintaining a strong bond. Wacquant asserts, “the atmosphere and mode of functioning of professional boxing gyms vary considerably with the personality, pedagogic style, and authority of their head coach, and secondarily as a function of their ethnic recruitment and status in the local or national boxing economy” (1995:492). The status of this particular gym and head coach are rising within the Parkinson’s community, which indicates a uniqueness of the experiences in this gym compared with others. This ethnography has attempted to illustrate the challenges of training with Parkinson’s and the benefits that can accompany this transition when done in a zone of empathic resonance, such as Coach’s gym. Future work may attempt to determine the effectiveness of this method with other coaches.

Lastly, there were times that an opinion expressed widely within the group was not shared by as many individuals as initially seemed to be the case. After two situated-conversations, a fighter disclosed to me that they had different feelings about the topic but did not want to dissuade other members of the group. I was only aware of this occurring when the discussion was about treatment options (such as Deep Brain Stimulation surgery), but I still made mental room in my analysis for the fact that vehemently and/or widely shared opinions are not the full picture.

5.4 Into the Future: The Research

Like my research participants, I feel tremendous gratitude for having a place at the boxing gym. I never expected the emotional growth and wisdom that came from spending time with honest to goodness fighters. I was humbled to be lovingly welcomed into their community and at times astounded by the abundance of valuable data that poured from my computer speakers. One of the hardest lessons that I learned was focusing my analysis. There are still research questions that I would like to explore with the Parkinson’s fighters. For example,

hallucinations and altered states of consciousness deserve further contemplation as players in a uniquely complicated ecology of the mind. Additionally, in the realm of neuro-anthropology, I would like to examine models of biocultural process of embodiment that consider the role of heat and haptic experience within the body. Heat is a “trans-boundary sense” that connects the internal embodied experiences with the external environment and has been recognized as an essential element of the athletic experience (Allen-Collinson and Owton 2014:245). Participants often mentioned missing the feeling of hitting a bag (or padded body) during the lockdown. The haptic element was immensely satisfying. Without it, boxing was still worthwhile, but the extra feedback from the fist making contact provided greater gratification (and I would guess neuromodulatory effects).

The “future of aging” also presents many areas of research and innovation that would benefit from the exploration of atypical aging experiences, particularly as such groups are increasing in numbers dramatically. The patterns and types of Parkinson’s degeneration when compared to phenomenological experiences and ethical subjectivities may provide valuable insight into the mind-body cognitive connection. Comparing Parkinson’s fighters with more sedentary groups with Parkinson’s or vocal training groups (as opposed to physical training) could elucidate more clearly how certain practices interact with motor disorders to alter embodied trajectories of disease.

5.5 Into the Future: The Gym

“You have millions of years of friends here.” - Dynamite encouraging me to stay involved.

5.5.1 Coming back from COVID

In March of 2020, the news went out that the gym would be closing for safety measures as Californians were given orders to shelter-in-place. One year later, the gym reopened for

personal training sessions. Boxers could pay for one-on-one classes with Coach or split the session up to three ways and box with a couple of friends. These meetings were not covered under their normal membership and lacked the social component that accompanied the typical workouts, but many fighters chose to take advantage of the opportunity for more face time with Coach. One month has passed, and today the group of (fully vaccinated) fighters are gathered on Zoom having just completed a workout. I'm about to begin a discussion about creativity for anyone who wants to stick around (usually nearly everyone does), but Coach has first promised an announcement. In two weeks' time, in-person classes will be back on the schedule. There is less enthusiasm or joy in the group than I had expected to see. Granted, one of the symptoms of Parkinson's is an understated outward expression of emotion despite the internal experience, but this does not affect everyone and typically there would still be a witty remark or whoop for joy upon hearing good news. "Maybe they were just recovering from the workout," I thought.

There would be some restrictions to the in-person classes at first. For one thing, masks would be required - a caveat that Coach had not been enforcing among the vaccinated fighters during personal training sessions. For the glasses-wearers, this is a troublesome and frightening proposition because their breath fogs up their spectacles and diminishes yet another physical ability. Also, the classes cannot be larger than 6 people and will require signing-up ahead of time. For everyone else, there would still be a zoom class in the morning. Because of the limited class size, Coach requested fighters only come into the gym one day a week and stick to zoom for the other days. Finally, to accommodate this new schedule, the length of class is being shortened from 90 minutes to 60 minutes. In order to fit this time without losing the exercise benefit, the get-to-know-you question that usually initiates their time together is being cut. The fighters were generally OK with that last bit of news. "After this past year, we all know each

other pretty well!” Many questions about the expected changes follow the announcement, and it seems that the reticent mood I had detected was not just a moment of catching their breath.

Things will be changing again.

The news must have gotten the group thinking because towards the end of our hour-long conversation, Viking asks me: “When you’re done with all of this, what are you going to do with us?” This is an easy question for me, but I’m glad to have the chance to express my intentions, if not slightly surprised by the objectifying way with which he spoke. “Oh, I’ll still hang out with you!” I respond truthfully. I had already gotten the approval to start volunteering in person again after assuring Coach that I had been vaccinated and confirming that I would be needed. This group has been as beneficial to my personal growth as they were to my academic career, and I’m deeply grateful. Sensing another concern, I add: “I’ll still do the zooms. We can still do Zoom happy hours even if the zoom boxing changes up a bit.” Viking seems relieved to hear this: “In many ways, I think they may become more important because we, we won't be able to socialize as much because we got to get back to the more physical. But now that we know each other so well, we're going to really care what's happening with people.”

The fighters cared about one another long before the pandemic, but this ordeal has brought the group closer together. It has become a place where they can speak candidly about their experience without being misunderstood as crazy or demented with a group of like-minded and similarly afflicted friends. Still, there is a feeling like the end of high school or any adaptive period of life that has been a trial- a reluctance to return to the way things were entirely, a pre-emptive nostalgia for the time that they had to get to know one another and explore themselves with Parkinson’s instead of concealing their quarks.

As I briefly mentioned earlier, Coach's reputation has taken off within the field over the course of the pandemic. Within the first couple of weeks of re-opening, four doctors (and former doctors) with PD join the gym, including an acclaimed epidemiologist. Coach proudly tells me that the ventilation has received approval from our new epidemiologist, whom he fully intends on consulting to make sure the fighters stay safe. His dedication to the class has not gone unnoticed and despite the virtual migration, the gym continued to grow. The practices that were developed for social distancing such as emails recapping the day's lesson with YouTube clips of the moves in action and virtual fight nights have remained in place. Being forced to think about including people who were not physically in the gym opened entirely new opportunities for connection that grew more durable relationships (as evidenced by Viking's remarks).

Not only is boxing growing in popularity as a therapeutic intervention against Parkinson's Disease, but the rates of the disease itself are increasing yearly in the United States. While other areas such as the European Union have made efforts to ban toxins that are linked to the development of Parkinson's (such as parquat), the United States has yet to protect their communities or hear the protests and lobbies petitioning for health regulations. Fascinating efforts have been made in stem cell and gene therapy research but a cure to the disease remains far on the horizon.

5.6 Concluding thoughts: The Journey to Justified

I used to feel uncomfortable with my fighter name being Justified, as I felt like the least justified person to be at that gym, yet I knew that the name was not given ironically. Neither was it given with great earnest. Most likely it had to do with the syllables being somewhat close to my actual name of Julia Sloane and sounding like a cool *nom de boxe*. The fighter who honored

me with this name quickly forgot that he'd been the one to come up with it (he is not suffering memory loss complications), and Coach was surprised he hadn't already used it. As my role at the gym settled, I provided a platform for justification that I did not appreciate until months into data analysis. Whether serendipity or fate, the concept of justification became thematic in my research. There is value in hearing that your embodied reactions were justified given the context, and as mentioned, I received multiple thank you emails after different ring-side chats expressing gratitude for the opportunity to connect on this level with others.

Creating a digital field site for my participants turned into an incredible gift in moments of separation. Access to the information that I was collecting was especially reaffirming to people distanced from their community (as is the case with many health disorders). Expanding the conversations to include all genders led to a deluge of information that had been previously relegated to side conversations over the years. Fighters were eager to inform the larger group on their niche knowledge and collect the knowledge acquired by others. There is a specific satisfaction that we get as humans when we are able to make a valuable contribution to our group.

Parkinson's is essentially an earthquake in the grounded cognitive experience of daily living that requires biomedical and social emotional support to address, along with an intentional engagement of body and mind that reaffirms personhood and ownership over the illness narrative. The gym offers a well-tailored cultural resource for meeting these needs. The positive social cognition of the group bolsters resilience in the individual that can be called upon when embodied cognitions are disrupted by Parkinson's. Ethnographic accounts that illustrate the effects of zones of empathic resonance provide greater insight into the interpersonal dimensions

of skill acquisition and enculturation. Processes of meaning-making and identity (re-)construction unfold on cultural, familial and personal levels.

Anthropological literature on aging details the unexpected new roles and socio-economic practices older adults have crafted in societies around the world as global demographics shift in age composition (Buch 2015a, Kinsella 2009, Sokolovsky 2009, Yarris 2017). Shadowing the elongated average human lifespan is the temporal necessity to develop culturally appropriate mechanisms of being-in the world in a body that is declining in mental and physical performative ability. Finding appropriate resources for refashioning ethical subjectivities is complicated further by degenerative conditions with distinctly different temporal orientations to daily life. Even fewer of these resources exist for minority groups (such as women and non-English speakers in the US).

Humans are remarkably adaptable creatures, but cultural affordance must be made for the variety of embodied modes of being and interacting with the world. These are particularly needed for individuals with different physical capabilities and aging bodies. Boxing is an excellent retirement project. Training like a boxer is tremendously helpful to aging as long as headshots are avoided. It provides an outlet for frustration, a zone of empathic resonance that re-affirms personhood and relational value, and it affords meaningful engagement between mind and body that generates vitality and resilience. “Without Parkinson’s, we wouldn’t have boxing,” shared Mustang. No matter the age, having the ability and reason to fight is a motivating factor for staying alive and active. While none of the fighters would choose to have Parkinson’s, they appreciate the fight.

Appendix A

“Ring-side Chat” Situated Conversation Topics

Bothering Ladies About Boxing (BLAB)

BLAB 1- 5	No topic.
BLAB 6	Coping tools
BLAB 7	Boxing and how it feels
BLAB 8	Successful Parkinson’s management
BLAB 9	Stress
BLAB 10	Experiences of Agency and Parkinson’s
BLAB 11	Participating in research
BLAB 12	Family
BLAB 13	Ethics in healthcare
BLAB 14	Confidence
BLAB 15	Motivation
BLAB 16	Relationships (romantic and platonic)
BLAB 17	Experiences of space
BLAB 18	Freezing of Gait (FOG) (participant requested)
BLAB 19	Comorbidities (Emergency Room experiences became a salient part of this discussion)
BLAB 20	Dealing with transitions

All Fighter Happy Hours

AFHH 1	Untraditional strategies and remedies
AFHH 2	Parkinson’s tough – success stories
AFHH 3	Stress
AFHH 4	Depression and mood hijackings (participant requested)
AFHH 5	Parkinson’s management and unexpected experiences

AFHH 6	Communication
AFHH 7	Creativity
AFHH 8	Relationships and community
AFHH 9	Why boxing
AFHH 10	Surprising side-effects (from boxing and Parkinson's)

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