

Bodies at the Intersection of Dance and Illness

by

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Introduction

From the Intersection of Dance and Illness

*“Our Father in Heaven, hallowed be your name,
Your kingdom come, your will be done,
On Earth as it is in heaven.
Give us today our daily bread, and forgive us our sins,
As we forgive those who sin against us.
Save us from the time of trial, and deliver us from evil.
For the kingdom, the power, and the glory are yours,
Now and forever. Amen.”*

These words, the Lord’s Prayer, were some of the last coherent words I heard my father’s mother utter. The last time I heard this from her, she had been suffering from stroke-related dementia for over five years. There was something about the history and cadence of these words that stayed in my grandmother’s mind while everything else seemed to disintegrate. This phenomenon is seen widely with mental disease; even those that are the most afflicted with dementia or aphasia are able to recite songs or poems seemingly without any difficulty.¹ The concept of what is so deep in one’s mind that it remains intact in the drudges of mental disease, struck me as poetic and particularly relevant to embodied dance research.

As a dancer, I rely on the integrity of my body and my brain to enact movement and to repeat it later, eloquently and artistically. My body, while far from the ideal “classical dancing body”,² is capable synthesizing and creating much of the movement material presented to me on any given day. This able-bodiedness has always seemed essential to my dancing. But what if it isn’t?

¹ This phenomenon has garnered recent fame in the recovery story of Congresswoman Gabrielle Giffords, who suffered from extreme Broca’s aphasia, an inability to produce words, after a gunshot wound to the head. Katie Moisse’s ABC Special, “Music Therapy Helps Gabrielle Giffords Find Her Voice After Tucson Shooting” shows her wordlessly sobbing in frustration one minute and singing “This Little Light of Mine” effortlessly (“Music Therapy”).

² See Chapter 1.

After working in the rehearsal studio for over 14 years, I have developed myself into a dancing body – but this body I have created does not just encompass my physical abilities and limits. As a dancer, I also think as a dancer and create as a dancer. It has become an innate part of me that I do not think I could ever lose entirely, no matter what physiological issues I encountered. This parallels the above prayer – there are aspects of dance that become engrained in a dancer, impenetrable to pathological forces.

The body, as studied in this research, is both a vulnerable and a powerful object. What emerges when these two seeming distinguishable factors coincide? This is what I am interested in with this work. I am studying three manifestations of this collision. Bill T. Jones established himself as a formidable dancer and choreographer before his body and the bodies of his peers began to weaken from illness. How does one who is able and powerful on stage deal with physical vulnerability? The Dance for Parkinson's group consists of people who have already established identities as ill-bodied – what happens when they develop the strength of a dancer?

My embodied research is the third manifestation of this crux between the body as vulnerable and as powerful. I spent a year developing two works for the stage, *Cement* (2013) and *Attachment Behavior* (2014) that focused on Alzheimer's dementia. Each of these pieces was created entirely with trained, able-bodied dancers. In the rehearsal process, I explored what the able body process and the dementia body process could give to each other. This was a study in embodiment. While I had a goal of giving the audience insight the pathologies and complexities behind the Alzheimer's illness, I did not put as much energy into creating an obvious and

instructive lesson, but rather I focused on the rehearsal process, and what came to the stage was what was able to be gleaned from this intersection of able- and ill-bodied.

My interests in this intersection not only lie in what can be gleaned from illness for the dance world, but how the dancing body can influence the perception of illness. I approach this topic not only as a trained dancer and choreographer, but also as a student of health and sciences. Studying the body through the lens of what it can accomplish through movement yields a different perspective on disease and pathology than what is learned through isolated hard science. Even those diagnosed with a disease strive for health – a holistic health that is attained not only by medicine, but also mind-body connection, community, and self-preservation. And in this holistic view of health, one finds dance.

Chapter 1

At the Intersection of Dance and Illness

With the title of this research, I am drawing a line – I am exploring “illness”, not “disease.” The distinction between the two of these is blurry, yet of serious consequences to the topics that I will cover, and not cover, in this work. “Disease” can be associated with the specific pathological entities of physiological systems – strokes, brain tumors, skin lesions, tremors – and seems to act as a title that one can give to the cause or groupings these entities. Someone with “Parkinson’s Disease” *presents* with tremors and muscle degradation, *caused* by accumulation of Lewy bodies and deficient dopamine production. It is these physical pathologies that make up a “disease,” which is thought to be consistent across all populations. Destructive pathologies will cause similar destruction to any human body system.³

“Illness,” on the other hand, incorporates the subjectivity and experience of the diseased. Helman describes “illness” as “the patient’s perspective on his ill-health,” which “depends on a number of factors.”⁴ This emotional response to one’s disease and symptoms can be influenced by an incalculable number of factors, like social surroundings, cultural background, perceptions of the disease, perceptions of what others think of the disease, or level of caretaking. While a disease nearly always accompanies illness, as it will be thought of in this research, it is important to note that the two are not synonymous and can even exist exclusively.⁵

³ C. G. Helman, "Disease Versus Illness in General Practice," *Journal of the Royal College of General Practice* 31.230 (1981): 548-552.

⁴ Helman, 549.

⁵ Hypochondriasis can be thought of as illness without disease, whereas patients with asymptomatic hypertension or early cancer patients can experience disease without any illness for some time (Helman, 551).

While there is historical and current research into the intersections of dance and disease,⁶ my focus here is the intersection of dance and illness. With the study of illness, I am able to look into perceptions and realities of the ill body, as well as its physical symptoms, and how this has shaped the establishment of dancing bodies. With “illness” established, I turn my attention now to the title of this chapter “At the Intersection of Dance and Illness.”

There are significant topics that one must be aware of when attempting to analyze the bodies of dance and illness. Firstly, what is a body, specifically, a dancing body? The classical dancing body as established by social and historical norms in the field is a far cry from the one often found in a hospital bed. The limitations of the ill body can lead to tremendous artistry, if not the artistry originally imagined by Balanchine or Diaghilev. This idea of the classical dancing body will be defined later in this chapter, and questioned in Chapters 3 and 4. Secondly, one must look at what is to gain by studying illness through dance. Illness is exhaustively researched by physicians, chemists, psychologists, and countless others – what do artists, both those suffering from illnesses themselves or not, have to contribute? One important example, which initially spurred my thinking on this topic, will be described further. Finally, the nature of “illness,” as defined above, gives way to the formation of a new identity. This identity is linked to the disease and is often emotionally and psychologically difficult to accept, particularly when illnesses such as AIDS, Parkinson’s, and Alzheimer’s take such a tremendous toll on one’s outward

⁶ For example, the “dancing plague” of the 16th century attributed the symptom of crazed dancing as a direct result of infectious disease (Waller). Currently, there is research into movement therapy to help patients suffering from various mental and psychological diseases (Meekums, Payne).

appearance and personality. This identity of debilitation has consequences on one's identity of a "dancer." How are these two identities at odds? Are they?

Body, Mind, or Brain

The separation of body from mind, and mind from brain, is an extremely active topic in modern medicine, particularly in the realm of organ donation and regenerative medicine. While the discussion around organ donation may seem off-topic here, this conversation has led to intense discussion about drawing the line between body, mind, and brain that shapes the way we can think about these objects in the more general field of dance and illness. With medicine today, one can be declared "brain-dead" and their body kept alive through artificial means. Clinical death, the official death of the person, necessitates "loss of function of both the brain and the mind."⁷ Further, the notion of life implies "that the cells are at some level functional and responsive."⁸ It can therefore be extrapolated that the living body, if maintained metabolically active, is not a qualification for life, but a living brain and mind are. However, this also raises the question, is a living brain synonymous with a living mind?

Scientists and philosophers may answer this question differently. In the medical world, where most attention is given to quantifiable and concrete topics like cellular and bodily matter, the mind is less understandable. Burd et. al refers to the mind as "the conceptual vehicle used to communicate many of the brain activities

⁷ Larry Burd, Jennifer M. Gregory, and Jacob Kerbeshian, "The brain-mind quiddity: ethical issues in the use of human brain tissue for therapeutic and scientific purposes," *Journal of Medical Ethics* 24.2 (1998): 118-122.

⁸ Burd, et al., 119.

which have yet defined either anatomical or functional localization.”⁹ It is concretely tied to the brain’s activity, and therefore its life is linked to the brain’s. The separation between life and death is therefore aligned between the brain and the body.

Philosophically, more emphasis is placed on the mind, while the brain becomes an integrated part of the body. Descartes defends the “natural immortality of the mind,” and therefore the life, in that “decay of the body does not imply the destruction of the mind.”¹⁰ With this point of view, the line between life and death is placed between the body, including the brain, and the mind.

I approach these three topics – brain, body, and mind – with the perspective more closely aligned with the medical view than the philosophical. Throughout this thesis, I refer to the mind when considering memory or experience, and brain when referring to biological ideas or illness processes. However, it is important to note that I consider the two intimately linked, following from the intimate link between physiological illness and the illness experience. Finally, I must define for this paper my conception of body.

With the title of this work, “Bodies at the Intersection of Dance and Illness,” I imply the importance of the body in both the illness and dance experiences. I approach the definition of body as both a scientist and a dancer. I recognize the body as a discrete set of organ systems, able to be physiologically plagued by disease. However, my definition of body also encompasses what the body is able to accomplish, particularly through its actions and movement. Throughout this work I

⁹ Burd et al., 118.

¹⁰ Liam P. Dempsey, "Thinking-Matter Then and Now: The Evolution of Mind-Body Dualism," *History of Philosophy Quarterly* 26.1 (2009): 43-61.

refer to the “dancing body” and the “illness or ill body.” Both of these terms include both the physical movement or disease process, but also the experiences that come with those physical processes. For dancing bodies, this incorporates the image and expectations of these bodies (see “Classical Dancing Bodies below) and the personal identity of a dancer. The ill body, in contrast with the well body, is also comprised of the stigma or identity of a diagnosed person (see “Illness Identity/Dancing Identity”) and the body’s limitations. Therefore, the “bodies” that intersect with dance and illness can only be described as such, and not isolated as purely physical beings, biological beings, stigmas, or experiences. As Susan Foster states, “Illusive, always on the move, the body is at best *like* something, but it is never that something.”¹¹

Classical Dancing Bodies¹²

“As a regulatory type, [the dancing body] is: upright (straight), lean, compact, youthful, able-bodied, and feminine (male or female).” Carol Brown¹³

The description above is typical of what one might imagine seeing on a proscenium stage. Professional dance companies, classically ballet companies, are inundated with this body type. The dancing body primarily exists, for the general public, as a spectacle on the stage, and acts to satiate “an appetite for consumption within commodity capitalism.” This fetishization of this body on stage is what makes it desirable as a product – a product that is created not on stage, but in the rehearsal

¹¹ Susan Leigh Foster, “Manifesto for Dead and Moving Bodies,” *The Routledge dance studies reader*, Ed. Alexandra Carter and Janet O’Shea, 2nd ed, (New York; London: Routledge, 2010) 291-302.

¹² All descriptions of the classical body are taken from Carol Brown, “Unpacking the body (The cultural stereotype of the dancer’s body),” *Dance Theatre Journal* 14.4 (1999): 12-16.

¹³ Brown, 13.

studio. It is in the rehearsal studio where this ideal classical dancing body of the stage is both formed and eluded.

In the studio is where the dancer is “forced to consider the effects of ageing, illness and injury, as well as the less definable alterations in body composition from one day to the next.”¹⁴ As one works to master and manipulate one’s body into this classical image, they confront their physical limits and failings. The classical dancing body is virtually unattainable, and that is what makes it so appealing to the striving dancer or hungry audience. But what if these physical failings, which dancers confront in rehearsal, are not those that can be worked on through hours at the barre? It is with illness and injury that most dancers stop dancing. A torn ACL can put a dancer out for the season – their bodies are no longer “able” to dance.

What happens, then, when an illness begins to affect a huge fabric of dancers, as AIDS did in the 1980s? When the bodies of the masses are failing, can the idea of the “classical dancing body” really hold up on the stage anymore? This is the crux of Bill T. Jones’s choreography that is studied in this research. How does one maintain a dancing body on stage when their body is failing, and the bodies of those around them are disintegrating? Jones dealt not only with his diagnosis in his work, but the mass effects of terminal illness around him. And as one who came very close to achieving the “classical dancing body” in his dance training and performance, the study of how Jones dealt with the loss of this physicality is important for the study of dance and illness.

¹⁴ Brown, 13.

If Jones represents what illness does to the idea of the dancing body that is already established, the students of the Dance for Parkinson's program reflect the opposite. These students are attempting to establish themselves as dancing bodies while already dealing with a failing body. They are becoming dancers who cannot possibly attain the "classical dancing body." Does this mean that they are not truly valid as dancers? One of the participants in the class refutes this claim. Cyndy is a member of the Brooklyn Dance for PD program and participated in a showcase performance by the group recently. "Since Claudine [the choreographer] gave me the assignment to be a dancer," she said, "I had to be a dancer."¹⁵ Even without all of the physical abilities, when given a chance to embody "a dancer," these participants do it, honestly and without annotation. In this modern age, when a diagnosis does not confine one to a hospital bed, the definition of the "classical dancing body" still exists, but exists to be challenged by those who chose to challenge it.

Autopathography

Why use art to study illness? Those with debilitating illness have trouble advocating for themselves, either because of physical limitations, emotional limitations, or simply a lack of understanding by the general public of their condition. There are many avenues for tackling this divide; art, in its many forms, has often been at the forefront of this objective. Art has the ability to transcend the traditional boundaries speaking and teaching, and gives the interested public a less alienating perspective of disease than a traditional clinical description.

¹⁵ *Capturing Grace*, Dir. Dave Iverson, 2014, DVD.

Tamar Tembeck expanded the term “autopathography,” traditionally defined as “autobiographical accounts of illness or suffering that take a narrative form,” to the visual realm.¹⁶ Hannah Wilke and Jo Spence, a multidisciplinary artist and a photographer, respectively, both chronicled their journeys with cancer through photographic autopathographies. These works serve as a type of catharsis for the artist – a way to contextualize and abstract their pain and suffering – as well as a method of shaping audience or viewer reception. As Tembeck puts it, “Viewers are typically torn between embracing or refusing empathy towards the image and toward the subject depicted.” This reflection that these works require of the audience place an intense gaze upon the realities and complexities of the diseased body.

An even more complex autopathography, I would argue, was created by William Utermohlen, an American artist. After Utermohlen was diagnosed with Alzheimer’s disease in 1995, he began painting and drawing self-portraits; this task resulted in a haunting series of works chronicling his demise into debilitation that have been exhibited in the New York Academy of Medicine, written about in countless publications, and have gone “viral” on the internet.¹⁷ Through an abstract, artistic manner, Utermohlen has been able to share some intimate information about the experience of living with Alzheimer’s dementia, and the public was able to grasp this knowledge, and empathize. While a cancer progression, as chronicled by Wilke and Spence, may be more accessible to a lay audience, Utermohlen’s seemingly incomprehensible abstracted results of the dissipating brain are perhaps more

¹⁶ Tamar Tembeck, "Exposed Wounds: The Photographic Autopathographies of Hannah Wilke and Jo Spence," *Canadian Art Review* 33 (2008): 87-101.

¹⁷ Denise Grady, "Self-Portraits Chronicle a Descent into Alzheimer's," *New York Times* October 24, 2006.

compelling. The ability inherent in art forms to do this is what drives my choreographic research into dementia.

As it was hinted at in the introduction to this work, I grew up with two grandmothers who suffered from severe dementia. My paternal grandmother suffered a stroke in 2006, and has been steadily declining ever since. My maternal grandmother has Alzheimer's dementia that has made her happy and toddler-like since my grandfather's death. My paternal grandmother moved to an assisted living facility in my hometown of Decatur, Georgia in 2009; since this time I have spent more time with her, inside and outside of this facility. From this experience, I began to intimately witness the treatment of those with severe dementia. My grandmother lives on a locked third floor of the facility, filled with others in similar conditions. Most days, she is shuffled from her room to the common space, where she is tucked away in a chair in the corner, only to be bothered at bath and meal times. This is the easy way to deal with those with dementia – treat them as if they cannot be understood or empathized with. It is true that relating to those with severe dementia is difficult, but it is a great shame that most believe that it is not worth their time. From my experience, they seem to believe that because the afflicted persons cannot outwardly express their thoughts or emotions like the well, that these thoughts or emotions must not exist in the same way.¹⁸ Surrounded by my grandmothers, this dismissal always seemed to be a great mistake.

¹⁸ “Persons with [Alzheimer's Disease] have identified feelings of disempowerment, labeling, stigmatization, and banishment resulting from social interactions” (Barbara Berger, and Sandy C. Burgener, "Measuring Perceived Stigma in Persons with Progressive Neurological Disease: Alzheimer's Dementia and Parkinson's Disease," *Dementia* 7.1 (2008): 31-53). Research has shown that this significant stigma toward is associated with an Alzheimer's or dementia diagnosis, resulting in

It is on the stage, like Utermohlen did with his portraits, that I have tried to inform the audience with some more intimate knowledge of the dementia illness. In *Cement* (2013), I created a stage full of the neuropathological complexities of the disease, abstracting the clinical knowledge important to understanding Alzheimer's dementia. By imitating this neurologic complexity onstage, I also reflected the persistent thought and brain activity in these patients, thought by many to be completely lost. In *Attachment Behavior* (2014), I focused on the choreographic research of well bodies (of my dancers) experiencing dementia-like symptoms, thereby informing my dancers, as well as the audience, of a deeper knowledge and experience of the disease.

Illness Identity/Dancing Identity

Anthropological and sociological “identity” is defined by a sense of being and belonging to some sort of socially recognized group¹⁹. Humans spend tremendous amounts of energy cultivating themselves into a certain group, but external and internal factors often influence the group to which one belongs. A diagnosis of an illness falls into both the external and internal categories of these factors that influence identity. Diagnoses “stamp” the ill person “with significance often unwanted and neither easily warded off nor coped with.”²⁰ This external, cultural stamp automatically creates a stigma on the diagnosed person's identity. Right off the

feelings of shame in the person with dementia and their caregiver and decreased care from outside sources (See Werner, MacRae, Berger et. al. and Graham et. al. for further discussion of this stigma).

¹⁹ K.A.Y. Deaux and Peter Burke, “Bridging Identities,” *Social Psychology Quarterly* 73.4 (2010): 315-320.

²⁰ Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition*, (New York: Basic Books, 1988) 26.

bat, the cultural concept of their diagnosis reduces one's agency in developing or maintaining a unique, personal identity.

Ann Cooper Albright views this cultural stigma as an attempt to deal with deviancy. This culture “works so anxiously to control the body's functions, desires, and physical boundaries, the disabled [or sick] body is immediately positioned as deviant, simply because it is a little messier, or because it takes a little longer and travels a little more circuitously to get to its destination.”²¹ This deviancy can be related to actual physical symptoms of the illness – a person with trouble walking or moving from Parkinson's Disease may be thought of as incompetent or unworthy of time due to the difficulty of working with them. Additionally, the diseased body can be viewed as deviant just because of the identity of the disease and its associations. For example, someone diagnosed with HIV can be labeled as sexually promiscuous or dirty, no matter the route of infection.²²

There are also the internal factors at play in a diagnosis that alter self-identity. Arthur Kleinman, M.D., extrapolates phenomenologist Helmuth Plessner's theory that “each of us *is* his or her body and *has* (experiences) a body.” By this thought, “the sick person is the sick body and also recognizes that he or she has a sick body that is distinct from self.”²³ By creating this distance between the illness and the “self” experiencing the illness, people are able to cultivate a sense of identity in relation to their diagnosis.²⁴ This identity can be of a fighter, a survivor, a defender of

²¹ Ann Cooper Albright, *Choreographing difference: the body and identity in contemporary dance*, (Middletown, Ct.: Wesleyan University Press, 1997) 60.

²² Kleinman, 22.

²³ Kleinman, 26.

²⁴ Kleinman refers to the experience of illness, particularly serious, chronic illnesses, as one that “converts the once born into the twice born” (Kleinman, 54).

previous skills and abilities. This internal distance allows the ill person the freedom to regain some agency over the identity and with what identity they will choose to interact with the outside, “well” world.

How do these factors, both cultural stigma and self-relation to one’s illness, affect the cultivation or maintenance of an identity of a dancer? Generally the cultivation of an identity as a dancer centers on copious training in order to develop a body that is capable of creating spectacle onstage. A dancer’s identity may be shaped by the classes they take, the choreographers they work with, how many leading roles they perform, and how well they are able to execute intricate movement – all of these factors create to the “awe” of the *dancer* on stage. When a dancer is diagnosed with a cultural stigma, are they still able to maintain this awe-inspiring identity? When one already suffers from cultural stigma of a disease, can they even attempt to develop this identity? Finally, how does one’s relation to their disease affect this development or maintenance?

The three following chapters have this paradox underlying their topics. The Dance for Parkinson’s program (Chapter 3) is an example of a group of already ill individuals developing a dancer identity. The work of Bill T. Jones (Chapter 2) chronicles the choreographic development of an established dancer in the face of personal diagnosis and loss of his social circle to disease. Finally, my choreographic research struggles with developing this diseased identity without an actual diagnosis by those with an established dance identity (Chapter 4).

One’s identity and one’s body are intimately linked and this project could analyze all of its topics through either lens. I have chosen to work through the concept

of the body versus the identity due to my personal interests and familiarity with the body as a set of systems that are altered by disease. One's relationship to their body certainly influences their identity, but there are countless other cultural, societal, and historical factors that also influence the identity. While I will touch on some of these factors, due to their importance, I do not claim to be an expert in their analysis and will therefore focus on the analysis of the body, and how its representation and abilities are affected by illness.

Research

This research seeks to find these connections between dance and debilitating illnesses. How has and can dance be used to translate intimate knowledge and experience of disease? Further, can dance be used as a medium of coping with this knowledge and experience? I strive to investigate these questions through three lenses: survivorship in the work and critique of Bill T. Jones, an HIV-positive choreographer; "Dance for Parkinson's Disease," a program that is a result of the collaboration of the Mark Morris Dance Company and the Brooklyn Parkinson's Group; and finally, a year-long personal choreographic inquiry into the pathological and experiential consequences of Alzheimer's disease.

The work of Bill T. Jones has always had a particular focus on "survivorship," from his explorations into racism to his "Survival Workshops" in the creation of *Still/Here*. Jones is himself a survivor, currently living with HIV, after being diagnosed simultaneously with his late partner, Arnie Zane. Though some may argue otherwise (see "*Still/Here* (1994)"), through his work, Jones is able to transcend the

identity of a victim of illness and create work that focuses on community and identity in the face of disease. I will touch on three particular intersections of dance and illness in Jones's work: *Untitled* (1989), *D-Man in the Waters* (1989), and *Still/Here* (1994). In creating these three pieces, Jones is translating knowledge about illness to the public in different ways and to vastly different outcomes.

Secondly, I explore the Dance for Parkinson's Disease (PD) program. The Dance for PD program was founded in 2001 as a collaboration between the Mark Morris Dance Group and the Brooklyn Parkinson's Group as a series of dance classes for Parkinson's patients to explore physical creativity and artistry in a comfortable environment. It has grown into a global program that is beginning to change the way that persons with PD view themselves and their illness.

My research into dance and dementia began with the creation of *This is, is this. this is THAT' is-* (2012), in which I specifically explored the concept of aphasia, dementia-induced loss of speech, with the language of dance. From the performance of this piece and its reception, it became evident that dance was able to give the audience some intimate information about the experience of loss of mental function. What are the limits of this information? In my choreographic research for *Cement* (2013) and *Attachment Behavior* (2014), I have explored dance as tool for translating both pathological information of Alzheimer's disease as well as the complex experience of suffering from the disease. This research looks both at the process of creating work to translate this information as well as the final product itself.

Chapter 2

Bill T. Jones: Empowered Embodiment

Introduction

“Dance was about this body and what it wanted to taste, what it wanted to say. Who knew a body could talk?” Bill T. Jones²⁵

The body of Bill T. Jones is perhaps one of the most “talkative” in American Modern Dance, both literally and figuratively. Jones is an extremely vocal artist about his work; in my research, I came across at least five interviews he gave on *Still/Here* with only seconds of effort. Additionally, Jones is known for the extensive use of text in his onstage, particularly autobiographical text, which I will discuss later through its use in *Untitled*. Not only is Jones verbose himself, but also his landscape of works speaks widely to a variety of topics: politics, racial identity, and most importantly to this research, HIV/AIDS and survivorship.

The scope of Jones’s work through his career is massive, but most of his choreographic interests have basis in some personal experience or characteristic. The beginning of Jones’s work cannot be discussed without mention of his long-term artistic and personal partner, Arnie Zane. Zane was a photographer than Jones met at college at SUNY Binghamton; the two transformed themselves into dancers and choreographers and developed a symbiotic relationship of working and living. The duo, affectionately referred to as BillandArnie²⁶, began creating duets together that served as both their comments on the political, social, and artistic environment of

²⁵ Bill T. Jones and Peggy Gillespie, *Last Night on Earth*, (New York: Pantheon Books, 1995) 65.

²⁶ Jones, Bill T. et al., *Last Night on Earth*, 93.

New York in the early 1970s and their explorations into narrative dance forms that persisted at the time.²⁷

After the pair's work with Lois Welk and the American Dance Asylum, Jones's work started gaining more notice and his work began focusing on dance as a "perceptual exercise, as opposed to a story."²⁸ This postmodern ideology led to creation of works with more abstracted movement yet continual incorporation of autobiographical text. While Jones's insisted on formalism on stage, the movement continued to have either a background in a personal experience or a textual narrative.²⁹ Carl Paris describes Jones's "need to express his story physically, to, as [Jones] put it, 'wrestle with a composite of preconceptions, biases, and fantasies' was in practice at odds with the 'no to spectacle,' 'no to virtuosity' minimalism of Yvonne Rainer and her postmodern adherents."³⁰ With the formation of the company, Bill T. Jones/Arnie Zane and Dancers, in 1982, this insistence on formalism was further interrupted by the introduction of HIV/AIDS into Bill and Arnie's, and the company's, life. It became nearly impossible to establish pure formalism without the incorporation of bodily experience and narrative on health, illness, suffering, and grief.

Through his work in this period, Jones strove to maintain the body through its illness, giving it the ailing body dignity and presence. At the most basic level, Jones

²⁷ For example, Jones described their first duet together, *Begin the Beguine* (1972), as a "thumbing [of] our noses" at the art world's fascination with avant-gardism. Later in the 1970s, the pieces by Jones and Zane were narrative structures based on the "No Manifesto" by Yvonne Rainer (Jones, Bill T. et al., *Last Night on Earth*, 111).

²⁸ Jones, Bill T. et al., *Last Night on Earth*, 132.

²⁹ *Blauvelt Mountain* (1980), which Jones describes as an exercise in dance perception and movement "constructivism," included audible word improvisation on race and societal impressions and was praised as a homoerotic work (Jones, Bill T. et al., *Last Night on Earth*, 148).

³⁰ Carl Paris, "Will the Real Bill T. Jones Please Stand Up?" *The Drama Review* 49.2 (2005): 67.

embodies the “classical dancing body”³¹. He grew up both an athlete and stage performer, perfecting both his physical form and his body’s coordination and artistry. His dancing form as made him famous was developed in college through rigorous training and personal explorations into choreography.³² However, when he was diagnosed with HIV and Zane was diagnosed with AIDS in the early 1980s, this crafted body began to take on a new form. As an eloquent technician of movement, what was to come of Jones’s work when his body, and those around him, began to fail?

In looking the development of Jones’s work in relation to the diseased body, I am focusing on three works: *Untitled* (1989), *D-Man in the Waters* (1989) and *Still/Here* (1994). *Untitled* (1989) was among the first pieces Jones choreographed after the death of Zane in 1988. In the work, Jones explores his visceral reaction to the ultimate destruction of the body by disease. This piece is perhaps Jones’s most personal in the scope of his works in relation to disease, as after Arnie’s death, he began to explore the consequences of disease, both on the body and on the spirit. *D-Man in the Waters* (1989) was imagined out of Jones’s impressions of the patterns of disease through the bodies of those around him. Finally, in *Still/Here* (1994), which was created some years after the compounded AIDS deaths of those around him, Jones explores the diseased body with more distance, choosing to focus on the larger

³¹ See Chapter 1.

³² In describing his body in its early training at SUNY Binghamton, Jones states, “My feet were big, flat, and did not have high, supple arches. I was not lithe and swanlike. My buttocks were hard and pronounced. My chest was barrel shaped, and it jutted forward. My shoulders were muscled with great affinity for my ears. My carriage was low, grounded, and round, not pulled up, elongated, and gracefully vertical, as I would have wished. But I wanted to move through space on my toes, to turn effortlessly. I wanted a nineteenth-century sense of *plastique* – to strike a pose ephemeral, transcending the natural world” (Jones, Bill T. et al., *Last Night on Earth*, 85).

concepts of communality and survival experienced by those inhabiting terminal illnesses.

With *Untitled* and *D-Man in the Waters*, I place Jones's focus on the body itself and the disease, AIDS, which is ravishing it. Jones uses dance to explore the emotional reactions to the illness, the societal aspects of it, and its gripping power in the 1980s American dance community. These pieces take on a personal voice, and are inseparable from Jones's own HIV diagnosis. In *Still/Here*, Jones's voice becomes less personal, and the piece focuses on the particular abilities of the diseased body in general – its ability to create communities and instill a new identity of survivorship. While many of the participants in the creation of *Still/Here* are suffering from AIDS, the work also includes the exploration of bodies suffering from breast cancer, cystic fibrosis, and other illnesses. While these diseases certainly have some merit in the scope of this work, I will only give a brief description and history of the AIDS disease and crisis in 1980s America, as it is the disease that primarily affected Jones's work.

HIV/AIDS Epidemic Background

The CDC originally described what became known as AIDS as “the possibility of a cellular immune dysfunction related to a common exposure that predisposes individuals to opportunistic infections such as pneumocystosis and candidiasis.” This vague definition was included in a CDC report after a suspiciously large group of previously healthy homosexual men in Los Angeles were found with fungal infections, specifically *Pneumocystis carinii* pneumonia and candidiasis, in

early 1981. By mid-year, 111 of these abnormal infections had been reported, with statistics that would come to greatly influence societal reaction to the epidemic: “99% of patients were male, 95% were 25-49 years old, 94% were homosexual or bisexual, 77% were white, and, most important, 40% were dead.”

Acquired Immunodeficiency Syndrome can now be defined by “diseases, which are at least moderately predictive of abnormal cell-mediated immunity, in a person with no known underlying cause for cellular immunodeficiency.” After immunologic studies, T lymphocyte cells were found to be the main cell that was reduced by the diseases, and some kind of “infectious agent” was the cause. Studies in France, at the NIH, and at UCSF all identified a very similar retrovirus, under various names, which was determined as the AIDS-agents, now termed the human immunodeficiency virus (HIV). The clinical characteristics associated with HIV infection are a long incubation period, central nervous system and hematopoietic system involvement, and associated immune suppression. This long incubation period explains the difference between HIV and AIDS – an HIV-affected individual may not show symptoms at all.³³

With those unfamiliar with the epidemic, HIV/AIDS may not have an immediate connection to the performing arts. A blood-borne virus can be transmitted through many avenues and across many cultures of people, but the focus of the epidemic in the 1980’s centered on the homosexual population. The social and political implications of an illness that was killing gay men specifically due to their sexual acts were ripe for homophobic discrimination. The HIV/AIDS epidemic

³³ All background material from Jay A Levy, *Aids: Pathogenesis and Treatment*, Immunology Series, (New York: Dekker, 1989).

became deeply intertwined with homosexual politics of the 1980s. By making the illness sexual and political, the conservative public insisted on “making the private public,”³⁴ allowing for choreographers to enter the stage.

This transfer of private sexual life to the public sphere creates the ability for homosexual men who are already in the public eye, like Jones, to establish the dialogue for the art world. This is the environment where Jones establishes the body as a formidable object, one that both acknowledges its susceptibility and pushes past it, “refusing victimology.”³⁵ The scope of work covered here includes Jones’s formation of his own body as well as his experiences with the bodies around him. It is estimated that around 50% of the male dancers in the professional dance world are homosexual³⁶, so it is reasonable that a large proportion of these male dancers in the 1980s either were diagnosed with HIV or AIDS, knew someone who was, or was presumed have the illness. Therefore, together with the publicized nature of HIV/AIDS, the refusal to accept the concept of victimhood, and the sheer number of dancers associated with the illness, the dance world was a prime stage for the epidemic and its effects to be discussed. As Carol Martin puts it in her essay “High Critics/Low Art”³⁷, “In the age of AIDS [was] it really possible... for the performing arts to exclude people who [were] actually ill?”

³⁴ Randy Martin, "Allegories of Passing in Bill T. Jones," *Dance Research Journal* 40.2 (2008): 76.

³⁵ Martin, 77.

³⁶ J. Michael Bailey, and Michael Oberschneider, “Sexual orientation and professional dance,” *Archives of Sexual Behavior* 26.4 (1997): 438.

³⁷ Carol Martin, “High Critics/Low Art,” *Moving Words: Re-Writing Dance*, Ed. Gay Morris, (New York; London: Routledge, 1996).

Untitled (1989)

“When you’re grieving you’re really trying to find a way to connect with the person you’ve lost.” Bill T. Jones³⁸

Untitled was choreographed for the PBS program *Alive from Off Center*, and was one of the first works that Jones produced after Zane’s death in 1988. The piece, a solo by Jones, is performed completely in the nude, instigating a dichotomy of the strikingly powerful body of Jones and the recent corpse of his lover. The movement in the first part of the piece is “relentlessly physical,” Jones marches, lunges, and sweeps his arms as the voice of Zane clouds the stage – a recounting of one of Zane’s dreams in which he is actively trampled by oncoming bulldozers.³⁹

In this part of the work, Jones take on the ill body is one of incomprehensibility. As Jones stated in the above quote, this piece was about grief. I propose that the work is not just focused on grief of Zane as a person, but of his body as well. Zane’s body was an active, dancing body, capable of the movements Jones is executing in this piece, but his body was unfairly taken from him, rendering him incapable of the movement. The dichotomy of Zane and Jones’s body that the soloist creates on stage serves as a comment of his incredulity towards the destruction of Zane’s body.

In the second part of *Untitled*, this incredulity transforms into anger. The first words that Jones speaks on stage indicate a broken promise: “You said, ‘A system in collapse is a system moving forward.’”⁴⁰ While this is presumably a phrase that was

³⁸ David Gere, *How to make dances in an epidemic: tracking choreography in the age of AIDS*, (Madison, Wi.: University of Wisconsin Press, 2004) 125.

³⁹ Gere, 128.

⁴⁰ *Untitled*, Dir. Bill T. Jones, John Sanborn, Mary Perillo, et al., Post Perfect, 1989.

uttered to him by a dying Zane, Jones spits these words at the audience, not at some abstract or ghostly being. The phrase is repeated at us with growing contempt, suggesting Jones frustration and anger with not just Zane, or AIDS, but with a disease's ability to "collapse" a person and a body – a system.

The final scenes of the work present Jones dressing, protecting his body with his clothing, repeating textual phrases from the narrative – "A system in collapse-," "Do you remember?" – and pounding his chest with his fist. Here the susceptibility of the body, his anger at its ability to be destroyed, and his defiance toward death and disease cumulate into a passionate rage to both a theoretical Zane and the audience. The piece as a whole insists on the power of the body, despite a growing epidemic.

Untitled serves as a vivid example of Jones's use of autobiographical text in order to establish a firm narrative of his body's experience. Ann Cooper Albright surmised that Jones's body of work claimed "a voice within an art form that traditionally glorifies the mute body, ... [using] autobiography in performance to change the dynamic of an objectifying gaze."⁴¹ While a more traditional narrative form of grief or autobiography, like poetry or essay, may serve some of the same purposes as Jones's work, in that it strives to give some sort of catharsis to the writer, the power of the dance form like *Untitled* comes in its insistence on face-to-face observance of the body. Illness and grief take physical tolls of the body that are not translatable through pure text; Jones's interplay of text, movement, and presence make these tolls immediate for the audience, in all of their uncomfortable forms. Albright describes the viewers of this work as "forced to deal directly with the history

⁴¹ Albright, 120.

of that body in conjunction with the history of their own bodies,” making for an uncomfortable and intense experience.⁴²

D-Man in the Waters (1989)

“I had a daydream, almost a vision, in which I saw Damien and a myriad of friends, living and dead, in a body of water. Perhaps it was a lake as vast as the ocean, a lake emptied by an immense and unforgiving waterfall. This company of people was struggling against the current. Some had already drowned, others were grasping their comrades to save them, still others were swimming confidently, almost enjoying their effort.” Bill T. Jones in *Last Night on Earth*⁴³

D-Man in the Waters was conceived as a piece about “survival... under the multiple fronts of assault that the 1980s introduced,” not AIDS in particular. This is a fact that Jones reiterates to this day. In Jones’s 1980s, however, many of these “assaults” were, in fact, AIDS-related. The movement, “gestural details... lifted from the waters of life,” reflects the lives of Jones and his dancer/collaborators at the time, including Zane and dancer Demian Acquavella, whom Jones affectionately called “D-man.”⁴⁴

St. Luke’s Chamber Orchestra commissioned the piece by Jones in 1989, a year after Zane’s death and a year before Acquavella’s. Throughout the rehearsal process, Acquavella was gradually becoming more ill, yet refused to not participate in the work’s creation. This desire is what drove Jones’s above vision for the piece. The importance of the work in this context is not just centered on the movement material itself, but rather how it was enacted on stage from its premiere and onward. The piece

⁴² Albright, 121.

⁴³ Martin, R., 77.

⁴⁴ Martin, R., 78.

became a staple in the Bill T. Jones and Arnie Zane repertory, partially due to the spectacle of its premiere at the Joyce Theater on March 14, 1989.⁴⁵

Acquavella's body, at this point, was incapable of performing his part – yet Jones made him keep his promise to perform. Jones ended up carrying Acquavella onstage in the performance, executing the 'legs' of his solo while D-man did the arm gestures.⁴⁶ This unapologetic presentation of the seriously traumatized body among the rest of the energetic, defiant, fully able company brought even more focus on Acquavella's body and illness. In directly juxtaposing the diseased body against the well body, Jones creates the sense of penetrance of the AIDS crisis that he describes in *Last Night on Earth*. The body of AIDS is not an isolated one, but one that is integrated into social circles. This implies that while no one is "safe" from the disease, those afflicted with it, like Acquavella, are not going to sit around and wait to die either.

Additionally, the movement material is focused on displaying the bodily effort involved in rigorous movement material, paralleling the bodily effort involved in fighting illness and disease. However, the movement and the effort involved are not enacted as if towards a fruitless end, or death. The energy of the piece is "crazy" and "maniacal," and must be performed with the joy of being in an alive body, even one fighting for that life. Jones, while recently coaching the piece to a new cast, had to describe the performance style to those who had not experienced its creation and the environment in which it was created. He told them, "No, you're not going to a funeral; you don't want a pasted smile. But don't be afraid to make eye contact and

⁴⁵ Neil Baldwin, "D-Man in the Waters: Reflections, Observations, Histories," *Bill T. Jones/Arnie Zane Dance Company*, New York Live Arts.

⁴⁶ Jones, Bill T. et al., *Last Night on Earth*, 194.

smile. Because there was a time when those of us dancing it knew it was a privilege to be able to smile.”

Still/Here (1994)

“Do you feel like you are a part of an elite? Do you know something that the well do not know?” Bill T. Jones⁴⁷

Jones posed the above questions to members of the terminal illness community – those diagnosed with or recently recovered from AIDS, breast cancer, cystic fibrosis – in each of fourteen “Survival Workshops” that he hosted from 1992-1994. Each of the participants in these workshops was asked to openly speak and move about life and looming death, and their experience as sufferers of terminal illness. How did their disease teach them new information on what they love, what they need, how they feel? How does their disease define their sense of body? These workshops yielded not only details about individuals in the face of death, but also a sense of “communality” in the face of an “inescapable” end that faces us all.⁴⁸ The importance of the workshops, rather than simple interviews with survivors, was for Jones to grasp a sense of what is gained when those with terminal illnesses come together. This is the gist of what he is getting at when Jones asks his participants if they feel they belong to an “elite,” or “know something that the well do not know.”

Still/Here (1994) centered on this commonality of experience in the face of death and disease. For Jones, these workshops were first and foremost “a way of gathering material” for the piece. The “material,” as Jones describes it, is stories and

⁴⁷ Bill T. Jones, “A Meditation on Still/Here,” UVA Medical Center Hour, UVA Medical Center, Charlottesville, Va. 14 Nov. 2011.

⁴⁸ Nicole J Cunningham, “Still/Here: An Interview with Bill T. Jones,” *Discourse* 16.3 (1994): 78.

movement, “movement coming from a very emotional place because I ask them to capsule or crystallize their essential situation, dilemma, in a gesture.”⁴⁹ This material was gleaned by Jones through a series of conversations, trust activities, and movement creation tasks that all centered on the person’s experience in their ill body. By focusing on this experience, the complexity in the movement stemmed from the complexity of an inherent question of research of dance and disease: “Is your body in fact your enemy because it’s where the illness is?” Dance and movement are essential to answering this question – the integral paradox of the diseased dancing body forces the dancer to discover information that might be otherwise unattainable through other mediums. Jones describes the importance of movement in the workshops in the documentary Bill T. Jones: Still/Here.

“I think that movement is liberating. I think that movement is good for you. The body is a reservoir of all sorts of tension and dark forces, and it’s also a potential source of amazing energy. This thing wants to live; it’s a powerful engine. It connects with the brain a reservoir of images, dreams, fears, associations languages, and it’s potential we can’t even begin to understand. Movement begins to negotiate the distance between the brain and the body, and it can be surprising, what we learn about each other.”⁵⁰

Still/Here works in the space in between the body and the illness, in the relationship that the ill person has to their diagnosis. Like Jones references in the quote above, movement negotiates this space. Because of the openness of the Survivor Workshops, no matter how an illness has affected one’s body physically,

⁴⁹ Jones, “A Meditation”.

⁵⁰ *Bill T. Jones Still/Here with Bill Moyers*, Dir. Alice Markowitz and David Grubin, Films for the Humanities & Sciences, 1997, DVD.

each can create movement that is particular to their experience – their experience in that affected body. In fact, movement is the only true way to capture the essence of the ill body; it is the only honest representation of what one *can* do with their diseased body.

Still/Here had its American premiere on September 29, 1994 in Iowa City, Iowa. The piece opens with a prelude of gestures translated directly from workshop participants; these gestures become morphed and abstracted throughout the rest of the piece. On stage with the dancers are various forms of video: of the participants in workshop, of diseased and dying body parts, of Jones himself. Accompanying the movement and video is a score of both classical music and audio from the workshops. These elements combine into a complex, ornate drama enacted on stage that both establishes a communal opinion and acceptance of death and is a celebration of living. In fact, one of Jones's main objectives for the performances of the piece was to "get people going," as a terminal diagnosis inevitably does⁵¹.

Instilling a "diagnosed" identity into the public may have been Jones's goal, but this was far from the reception that *Still/Here* received. This piece has been so widely discussed since its premiere that it inspired a long discussion between critics about the value of art criticism. Prominent dance critic Arlene Croce attacked *Still/Here* in the *New Yorker* in 1994 with an article titled "Discussing the Undiscussable,"⁵² in which she marked *Still/Here* as the antithesis of dance as "high art." She derided the work as an "intolerably voyeuristic" spectacle in which Jones manipulated the audience into viewing victimhood as art. This article spawned many

⁵¹ Bill T. Jones *Still/Here* with Bill Moyers.

⁵² Arlene Croce, "Discussing the Undiscussable," *The New Yorker* Dec 26, 1994: 54-60.

responses, for many reasons. Croce's first offense was her refusal to see the piece at all due to its provocative nature; this act was criticized heavily by Richard Goldstein in *Village Voice*, who also berated her racist and homophobic overtones.⁵³ Others, like Frank Rich from the New York Times, criticized her lack of empathy and rash dismissal of the artists as "victims."⁵⁴ Critics call Croce reactionary, contemptuous, cheap; others, in true democratic fashion, defend her as staunchly as her critics. Needless to say, *Still/Here* launched a controversy that lasted years. The fact that this controversy emerged engraved *Still/Here* in the general public's mind as Jones's take on illness and dying. While the work did certainly serve as research into Jones's ideology on the subject, it was far from the only work that did to shape his thoughts and *that* was the real issue that the controversy and its fame caused.

Conclusions

"If the body can betray you, then who is the you that we're talking about?" Bill T. Jones⁵⁵

In the scope of this work, Bill T. Jones serves as the example of maintaining the dancing body despite and through illness. Jones approaches this task in his own body, and those of his dancers, of his partner, and of his collaborators in survival workshops. The above quote sums up the force behind Jones's work in relation to

⁵³ Goldstein wrote that "to condemn a work or art without even seeing it has a Helmsian, not to say Stalinish, stench... The vast terrain of her argument is a clue to Croce's real intention, which is to synthesize the arguments of the neocons into a primal scream against the values of contemporary art... That this critic must be coerced into empathy may explain why her prose is threaded with racist and homophobic aperçus, mostly directed at Jones" (Teachout, Terry, "Victim Art," *Commentary* Mar. 1995: 59).

⁵⁴ Rich in the NYT wrote, "To the extent AIDS is responsible for yanking death out of the American closet, history may show that the epidemic has changed our culture... this is the story of our time. Amazingly, Croce has missed that story, just as surely as she has failed to see that dying is a part of art because it is a part of life" (Teachout, 59).

⁵⁵ Cunningham, 85.

bodies and illness – while the body may betray you, embodiment will not. What do I mean by this?

Throughout this work, Jones worked with persons with HIV, AIDS, cystic fibrosis, and breast cancer, among others. Each of these illnesses has drastic effects on one's physiology and physicality; they change both the body and how one relates to their body. This relationship to one's illness is, often, as Jones describes, a betrayal. Arthur Kleinman portrays it similarly:

“The fidelity of our bodies is so basic that we never think of it – it is the certain grounds of our daily experience. Chronic illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair.”⁵⁶

This reaction is evident in all of the works studied above. In *Untitled*, Jones is mistrusting of his own body, and angry with the body, and destruction of the body, of Zane. In *Still/Here*, much of the movement was formed directly from the workshop participant's reflections on their distrust of their bodies. However, despite the presentation of all of this bodily betrayal, the embodiment of that betrayal serves to give some power back.

Acquavella forced himself to perform in the *D-Man in the Waters* premiere, even in limited capacity, restoring some of the dignity and performativity back in his AIDS-ravished body. By performing *Untitled*, Jones was able to enact his frustrations with the illness that had taken his partner, thereby re-instilling trust in his own body

⁵⁶ Kleinman, 45.

despite its HIV diagnosis. Finally, all of the participants in the survival workshops were able to use their bodies in a way that was not clinical or therapeutic, but artistic. Their power of their embodiment translated onto the professional dancers performing *Still/Here*, who through their own work gave even more power to the celebration of movement despite illness.

Jones's ability to create power by embodied performance is directly connected to his originally well body. Jones was a dancer, performer, and choreographer before illness began to enter his life. This allowed him to recognize the bodily trust that comes with embodied movement; performing movement yields a sense of confidence unlike any other. By being confronted with failing bodies, Jones was able to translate that frustration into empowerment through means he already had – movement.

Chapter 3

Dance for Parkinson's: "I'm a dancer; I have to sit up straight"⁵⁷

Introduction

"Dancing allows a body to that pisses me off by betraying me to move it ways which reconnect me and my body in a creative and fun way, making me feel like we're a team again." Leonore Gordon⁵⁸

This dichotomy of ailing body and active mind described by Gordon, a member of the Brooklyn Dance for Parkinson's Disease class, seems to be at odds with the identity of a dancer. Dancers rely on their bodies for grace and agility and their minds to process this kinesthetic information. Development as a "dancer" does not traditionally begin with a diagnosis of Parkinson's disease. Parkinson's disease (PD) is a progressive hypokinetic movement disorder⁵⁹ that is caused by death of neural basal ganglia cells. The healthy basal ganglia maintain muscular tone and coordinates movement, including the most autonomic of activities like walking. Specifically, basal ganglia cells that produce dopamine are destroyed; dopamine is a neurotransmitter that causes firing of neurons in the motor cortex, allowing for complex movement of the body and its limbs. With the destruction of these cells, the level of dopamine slowly declines and Parkinson's symptoms develop.⁶⁰

Nearly all of the Parkinson's symptoms affect how one would act on stage. Four "cardinal signs" characterize PD: rest tremor, rigidity, bradykinesia, and balance

⁵⁷ *Capturing Grace*.

⁵⁸ David Leventhal, "Think like a Dancer," *Dance Gazette* Sept. 2010.

⁵⁹ Hypokinetic movement disorders, like Parkinson's, are characterized as diseases that inhibit the body's ability to initiate movement and move fluidly. Hyperkinetic movement disorders, like Tourette's syndrome, result in excess, uncontrolled movement (Sharma, Nutan, *Parkinson's Disease*. (Westport, Ct.: Greenwood Press, 2008) 1-3).

⁶⁰ Steven J. Huber, and Jeffrey L. Cummings, *Parkinson's Disease: Neurobehavioral Aspects*, (New York: Oxford University Press, 1992) 10-24.

difficulties.⁶¹ The tremor is perhaps the most familiar symptom of PD. A tremor is a result of the oscillating firing of antagonistic muscles⁶² and often begins small in Parkinson's patients, and grows to affect the full body as the disease progresses. Bradykinesia is a general slowness in movement, noticed by many in the way that PD sufferers move when they walk. That these symptoms, along with rigidity and balance issues, would affect one's ability to dance seems immediately obvious to anyone familiar with the traditional iterations of the art form. And while PD may indeed affect one's ability to dance, the affectation may not be entirely negative, as the Dance for PD program shows.

The Dance for PD program emerged from a collaboration by the Brooklyn Parkinson's Group (BPG) and the Mark Morris Dance Group. Olie Westheimer, the director of BPG, originally approached the Mark Morris Dance Group about a possible collaboration for outreach. Westheimer, who had been trained in ballet had been running a traditional support group for Parkinson's patients when she noticed that several of the mental problem-solving techniques used by PD patients to deal with their symptoms mimicked techniques used by dancers. The balance-instilling technique of 'spotting', which one learns in the first few years of ballet training, involves focusing on one "spot" on a wall or room and blocking out what one sees while turning. This idea is precisely what Westheimer's patients described when they had to enact a sequence of movement without losing balance. "A professionally trained dancer has so much to teach someone with Parkinson's disease," Westheimer

⁶¹ Sharma, 10.

⁶² Antagonistic muscles are those that perform opposite actions. One example of an antagonistic pair is the biceps, which flex the elbow, and the triceps, which extend the elbow (Nancy Hamilton, Wendy Weimar, and Kathryn Luttgens, *Kinesiology: Scientific Basis of Human Motion*, (New York: McGraw Hill, 2012) 55-58).

realized. Not only did she believe that dance training could provide mental and physical problem-solving techniques, but also that dance would help aid in the depression that accompanies chronic illnesses and that it would serve to help redefine these patients. The persons with PD in the support group defined themselves as PWPD and CPWPD – “Persons With Parkinson’s Disease” and “Caregivers of Persons With Parkinson’s Disease,” and tended to spend a large portion of their time researching and thinking about their disease. Westheimer believed that a dance class that would train these people into something else, into “dancers,” would aid in their overall wellbeing.⁶³

The class was conceived as a once-a-week class for a small number of Parkinson’s patients, but the program grew rapidly. During the first year, there would be classes with only one participant; five years later, the class sizes ranged from 18-32, with participants spanning ages 50-90. Now, classes can have over 50 dancers with PD. Additionally, the level of impairment ranges among those in the classes, from the recently diagnosed to those who have been treated with deep brain stimulation.

The class functions as an adapted ballet class: warm-up at the barre for proprioceptive feedback, center work, and an across the floor movement sequence, all with live accompaniment. All of the material taught in the class is established modern dance movement, much of it repertory from the Mark Morris Dance Group (MMDG); none of the material is meant to be intentionally therapeutic. The teachers are MMDG company members; David Leventhal, now the program director, John Heginbotham,

⁶³ Olie Westheimer, *Gel Health*, New York City, 2009.

and Misty Owens have been developing the program for years. Heginbotham reflects, “My impression is that many people with Parkinson’s feel like they are outside of the human experience. And dance is a huge part of the human experience. And so, to come in and dance, you’re human again.”⁶⁴

Dance for the Parkinson’s Body

“Everything in dance training is geared towards getting the brain to think about movement.” David Leventhal⁶⁵

The initial rationale for choosing dance as a therapeutic tool in this environment was three-fold: the classes would provide ability for persons with PD to participate individually while still belonging to a social group; the movement would strengthen and stretch muscles while also promoting bodily awareness, balance, and a positive mood; and to teach those with PD cognitive, visual, and musical strategies for controlling movement and balance. Leventhal reiterates the fact that while much of the general public may imagine dancers as “athletes of God,” indicating some innate or gifted ability to dance, training actually starts in the mind.⁶⁶

One of the most integral aspects of these classes is the mental imagery given and created on the body. The instructors in the class rely heavily on the description of the movement to create a full picture of a gesture or movement in the participants’ minds. That way, even those with the most severe mobility issues can imagine themselves fully embodying the movement. Joy Esterberg, one of the dancers in the

⁶⁴ “Dance Helps Parkinson's Patients Harness Therapeutic Power of Movement,” *Newshour*, Narr. Dave Iverson, PBS 10 Dec. 2010.

⁶⁵ David Leventhal, “Enrichment Seminar,” Artists and Scientists as Partners, Brown University, Providence, Ri. 28 Feb. 2014.

⁶⁶ Leventhal, “Enrichment Seminar.”

class, describes enacting this imagery as bliss. “You extend your arm; you have an ideal sense of what an extended arm looks like. It doesn’t look like this,” Joy says as she extends her arm to its possible length, still slightly bent, “But if you try to do it, and, in your mind’s eye, you are feeling it and doing it utterly to the extent that you can imagine it, then you are there.”⁶⁷ This technique is not solely limited to those who are debilitated; professional working dancers in every class or rehearsal employ this strategy.

Among the other dance skills that apply directly to PD are repetition, balance, and movement creation. The aspect of repetition in dance helps to “reprogram” the neuronal system to help establish alternative pathways to successful movements. Dawn Fallik characterizes these alternative pathways as “doing the same movement over and over, reinforcing a toe-heel step instead of walking, a sideways grapevine, not a turn. That way, when a patient gets stuck, they can think of another movement and take that different map to get them to the same place.”⁶⁸ However, sometimes even enacting these different maps induces balance and gait issues. To focus attention to balance, the classes place focus on tactile feedback. Movements are performed “holding hands, in a circle or line, adding touch or somatosensory input to aural and visual inputs.”⁶⁹ This feedback creates comfort among participants and synchronicity in their movements, which helps to build confidence in movement. Finally, there is an emphasis on the participants creating their own movement, an exercise in “mental and physical concentration on movement, self-reliance, [and] cooperation.” Groups will

⁶⁷ “Dance Help’s Parkinson’s Patients.”

⁶⁸ Dawn Fallik, “Finding New Life through Movement,” *Neurology Now*, January/February 2007 (2007): 30-34.

⁶⁹ Olie Westheimer, “Why Dance for Parkinson’s Disease,” *Topics in Geriatric Rehabilitation* 24.2 (2008): 127-40.

follow behind a designated choreographer, another dancer in the class, moving to the music “in whatever way he or she chooses.”⁷⁰ This creative work increases kinesthetic awareness of the body.

Dance with the Parkinson’s Body

While the ideal goals of these classes as described above are great conceptual tools that connect the mental processes behind a dancing body to a Parkinson’s body, but how do they actually work? To describe the effects that these techniques have had, I can recount the story of one particular dancer in the Brooklyn Dance for PD class, Cyndy, as portrayed in Dave Iverson’s documentary film, Capturing Grace.⁷¹ Cyndy has advanced PD, and is shown with a nearly constant tremor. In one scene, she sits in her living room chair. When she tries to get up and walk towards Iverson, the characteristic Parkinson’s inability to initiate movement is clear. She stumbles forward in one step, unable to begin the next step. Then, she says, she reimagines her trek across the room as dancing. Suddenly, Cyndy begins chasseeing across the floor, gliding side to side, snapping her fingers. She easily makes it across the room and back. The Parkinson’s body is immediately and shockingly transformed from one that is incapable of movement to a graceful, joyful dancing body.

While the dance and its associated strength conditioning has been shown to stimulate dopamine production, improve balance, increase walking speed, and heighten the ability to release a Parkinsonian contraction⁷², most of the study in the

⁷⁰ Westheimer, “Why Dance,” 5.

⁷¹ *Capturing Grace*.

⁷² Dawn Fallik, “Why Exercise Helps People with Movement Disorders,” *Neurology Now* 3.1 (2007): 34.

success of the program must be focused on the individual bodily experiences. After all, successful dancing integrates all of these aspects into controlled movement; a successful dancer with Parkinson's would have to integrate these as well. One's ability to move is possible to analyze clinically, yet the deepest sense of that embodiment comes from the personal responses and stories from the dancers.

As a way of evaluating the success of this embodiment and its affect on the dancers, the program asked its participants to complete the 17-item Quality of Life Scale⁷³ after running 17 months of classes. This test aimed to "measure overall estimate quality of life, beyond issues only related to health." These tests revealed that the largest changes since the implementation of the classes were in three categories: "participating in active recreation," "socializing – meeting other people, doing things, parties, etc," and "health – being physically fit and vigorous." Around the same time, Misty Owens, one of the dancers leading classes, emailed five participants, ranging the Parkinson's scale, with questions on their experiences. The four questions and the key words in the responses are given below:

1. "How *does your body feel after our dance class ends? Please describe.*"

Key words: "much better, light, floaty, graceful, relaxed, invigorated, high energy, exhilarated, more flexible, symptom-free."

2. "How *do you feel in your mind after the dance class ends?*" *Key words:*

"run and leap, smiling, courageous, sorry it's over, much happier, a little spacey, good mood, focused and clear."

⁷³ This scale was created by the Oregon Health & Sciences University and was validated for persons with chronic diseases. In the questionnaire, participants answer 17 questions, on a scale from 1-7, about their satisfaction in health, relationship well-being, and personal/social activity. In its use for Dance for PD, the participants created scales for before and after taking the class, and these responses were compared to gauge effectiveness (Westheimer, "Why Dance," 7).

3. “Do you feel the consequences of the class impact your quality of life on a daily basis? How?” Key words: “fulfilling, empowering, optimistic, inspired, flexible, confident.”
4. “What do you believe specifically makes this dance class work for you? What brings you back to class each week? Please describe.” Key words: “promotes possibilities, interactions, participation, learning, feeling symptom free, hope, joy, being fluid and graceful, comfortable, anxiety-free, cheerful, enjoying the movements, connections with others, feeling great.”⁷⁴

This is not to say that the embodiment of a dancing body for those with Parkinson’s is an easy task to accomplish. One danger in this work is that the person with PD can feel like they are just playing a role as a dancer, rather than actually becoming one. This sense of falsehood can lead to feelings of isolation or failure.

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body. If embodiment as a dancer is the goal of this program, which I believe it is, and this embodiment must be achieved in isolation from thoughts about their illness, does the program qualify as therapy? This idea of therapy, while it may seem rather benign, is fairly controversial in regards to the Dance for PD program.

Dance Therapy/Therapeutic Dance

“The neurologists are impressed with the wider gait, and the smoothness of action. The physical therapists ooh and ahh at the dancers’ control. And the neuroscientists whisper about mirror neurons in action. But we just see a group of dancers moving gracefully through space.” David Leventhal⁷⁶

Dance Movement Therapy (DMT) and therapeutic dance are often thought of synonymously, yet there are important distinctions. The Association for Dance Movement Therapy defines DMT as “the psychotherapeutic use of movement and dance through which a person can engage creatively in a process to further their emotional, cognitive, physical, and social integration.”⁷⁷ Two key factors that differentiate DMT from therapeutic dance are that DMT generally require clinical supervision and clinical diagnostic observation. Therapeutic dance, on the other hand, has an artistic and aesthetic, rather than diagnostic, emphasis. While artists typically facilitate both, DMT facilitators respond to therapeutic goals and the client’s needs, whereas therapeutic dance facilitators usually work with their own artistic or choreographic goals in mind.⁷⁸

The Dance for PD program does not seem to fall into either of these genres, and perhaps that is why it is so difficult to decide how to qualify it. In order to decide

⁷⁶ David Leventhal, “Dance for PD,” Parkinson's Disease Foundation, New York 2009.

⁷⁷ Bonnie Meekums, *Dance Movement Therapy: A Creative Psychotherapeutic Approach*, Creative Therapies in Practice, (Thousand Oaks, Ca.: Sage Publications, 2002) 4.

⁷⁸ Meekums, 6.

if the Dance for PD program is therapy, or in what sense, we must ask ourselves what the goals of the program are. As it was originally founded by Westheimer, as described in the Introduction to this chapter, the classes were a way for those with Parkinson's to spend time away from their diagnosis, doing something that was completely outside a life of hospitals and support groups. Therefore, the classes are not working with designated therapeutic goals and do not seem to fit into the DMT parameters. In creating the curriculum for the class, Leventhal and the other MMDG teachers strived to create a rigorous dance class that was, while adapted for those with PD with the use of chairs, not focused on aiding symptoms. This is still the way Leventhal, Westheimer, and the dancers see the program today.⁷⁹ Thus, the facilitators are not working with their own choreographic goals, though there are certainly artistic intentions built into the MMDG repertory curriculum. The classes may fit in some form into the "therapeutic dance" umbrella, but the facilitators do not view it in that manner.

In fact, Leventhal and his colleagues intentionally try to avoid any sort of clinical or therapeutic association with the class but not allowing any health centers or hospitals host classes. The program is spreading around the country, yet only designated dance studios or community centers can host classes, despite many interested health programs. "The medical industry would like this to be a therapy-based program," Leventhal recently stated, "because then they say, 'If it's therapy-

⁷⁹ "Parkinson's is so much in the forefront of their lives... This is a chance to put it on the back burner – it's just a dance class, we don't look at it like a therapy class," said Leventhal (Fallik, *Finding New Life*). Carroll Neesmann, a class participant, reiterated the sentiment: "The pleasure of the experience is that it's not a therapy session. They teach us as if we were any students, and that makes me feel good" (Roslyn Sulcas, "Getting Their Groove Back, with Help from the Magic of Dance," *New York Times* 25 Aug. 2007).

based then it's evidence-based and we can have it in our health center.'"⁸⁰ Making the classes into therapy sessions at a hospital would contradict many of the goals of the program, as this would remove the element of independence from disease.

Furthermore, making dance a therapeutic requirement would reframe it as something that the persons with PD *had* to do rather than *wanted* to do. The program succeeds because it allows these persons to separate themselves from their disease bodies and just do something for themselves.

However, even if the class does not "intentionally address psychological concerns or specific symptoms," as Leventhal emphasizes⁸¹, the classes have still been studied and analyzed as therapeutic tools. The Quality of Life scale evaluation was a form of scientific assessment, something that would generally accompany a therapy in order to judge its effectiveness. Furthermore, the class has developed dance exercises that specifically focus on Parkinson's problems, like opposition work or walking/marching exercises.

It is difficult to delineate between the intentions of the program and its consequences, but that is what makes this program so effective. The program works as a therapeutic tool for persons with Parkinson's precisely because it does not qualify itself as a therapeutic tool. The PD symptoms that the classes works to alleviate, those of balance, memory, strength, and social problems, are not actually addressed, allowing the dancers to fully immerse themselves in the work, and therefore the therapy. They are not bogged down into thinking that the program is

⁸⁰ Leventhal, "Enrichment Seminar."

⁸¹ J. Young-Mason, "Art, Body, and Soul: A Conversation with Dancers David Leventhal and John Heginbotham," *Clinical Nurse Specialist* 24.6 (2010): 323-26.

something that they have to do to help their symptoms; they help their symptoms by doing something completely different, inhabiting a dancing body.

Conclusions

I had the opportunity in February 2014 to attend the Artists and Scientists as Partners Symposium at Brown University, which focused on the work of the Dance for PD program. Included in the symposium were lectures on the Dance for PD program, a class with the program participants led by Leventhal, a showing of Capturing Grace by David Iverson on the Brooklyn Dance for PD class, workshops by dancers afflicted with PD, and panels with dancers, choreographers, doctors, researchers, and Dance for PD participants. One of the first points that David Leventhal emphasized about the program's importance was the following:

“With any chronic condition, we always run the risk... of becoming, essentially, permanently medicalized. That once you're identified as having Parkinson's, that identity as patient takes over everything else that you were for the previous 55 years – artist, lawyer, father, aunt, all those other things. You're still those things but when people see you it's like, ‘There's Joe; he has Parkinson's.’”⁸²

This risk that Leventhal describes is the confiscation of the self by the Parkinson's body and all that it entails. The physiological body is overrun with motor, cognition, and visiospatial issues,⁸³ which can easily lead the person to succumb the

⁸² This quote was part of a lengthy conversation about the program with dancers, therapists, and other medical professionals about the significance of the Dance for PD program (Leventhal, “Enrichment Seminar”).

⁸³ Sharma, 59-81.

rest of their personal, social, and psychological attention to the disease. The success of the Dance for PD program is in giving these people another body.

The body is one of flexibility, of artistic and creative endeavors, and of action. The dancing body becomes a distraction from the ill body, but also a healer of the ill body. For dancers with Parkinson's, movement serves to reinitiate connections between the mind and the body that have been lost, for the mind no longer directs a body that tries to fight and inhibit its every thought, but a body that listens and responds with grace.

Chapter 4

Dancing Dementia: Accumulation and Degeneration

Introduction

The concept of this research initially centered purely on dance and dementia. In the failing brain, there is so much at stake that concerns dancers – loss of memory, mobility, creativity, language. In widening my research, I realized that these losses are not only integral to the dancer’s body, but are global losses that accompany most debilitating illnesses, mental or otherwise. So I delved into research about Bill T. Jones, terminal illness, and Parkinson’s, but my choreographic eye was always firmly fixed to the dementia brain.

In choosing to choreograph work based on a pervasive, depressing, and drastic disease, I strived to create a teachable moment on stage, rather than a play for empathy. In my time with my grandmothers, I came to understand that dementia *is hard to understand*. Not only is the experience of the disease hard to relate to, but also the pathological complexities involved in the disorder make comprehending the pathway of the disease difficult for the layperson. These two topics, the dementia disease process and the experience of the dementia, are the foci of the two semester-long works, *Cement* (2013) and *Attachment Behavior* (2014).

In creating these works, I approach topics that may raise concerns similar to those that Croce objected to in Jones’s work - namely, that I abstract elements of illness into choreographic tools and staged performance. However, as opposed to deriving my information from which to base the works directly from those with dementia, the choreographic tools have bases in published scientific or clinical

research. Therefore, while there is nondescript inspiration from my personal experiences with my grandmothers, I do not extrapolate material from persons who could be labeled as victims.

I worked to give my dancers aspects of a diseased body within their established dancing bodies. As opposed to what dance can give to a diseased body, as was studied through Jones and the Dance for PD research, this choreographic research focused on what the diseased body can give to movement. Much of the work was experimental; I spent copious studio time playing with concepts of disease and illness and finding the most powerful aspects to translate onto the stage. Could these artistic abstractions of illnesses onto dancing bodies yield a deeper understanding of the disease and its consequences?

Cement (2013)

Cement was cast with an eye toward dancers that I knew had vast experience with multiple languages of dance in order to have a multitude of perspectives from which to inform the audience. The work consisted of three females, Chloe Jones, Stellar Levy, and Rachel Lim, and one male, Jonathan Sung. Chloe was trained from the beginning as a modern dancer, whereas Jonathan had roots in hip-hop and yoga; Rachel and Stellar both had diverse dance backgrounds. In this work I was looking into the medical progression of the disease, and I knew I needed dancers with the ability to translate this information on stage. This translation was the main choreographic goal.

The piece began with the set concept – I created a proscenium-wide “net,” of sorts, made out of gold chain that hung in front of the first wing on the stage. This served as both the lens through which the audience experienced the whole work and the representation of the disintegrating neural network of the dementia brain. Through the first function, the network symbolized this translation of information to the audience. From the moment the audience walked into the theater, their view of the stage and the work was obscured. Throughout the work, the dancers broke apart the connections of the chain, slowly revealing more and more of the stage, paralleling the slow gain of disease process understanding of the audience. In this set breakdown, the dancers were simulating the degeneration of the brain through the dementia process.

In the work’s prelude, the dancers walked in, around, and through the still-intact chain network to a narrative soundtrack by Dr. Matthew Schneiderjan, the neuropathologist that I research with. This audio track began as a pure two-minute physiological description of Alzheimer’s disease.⁸⁴ Midway through the description,

⁸⁴ “Alzheimer’s Disease is a progressive, incurable neurodegenerative process wherein the affected individual, most typically elderly, loses mental function over time. The fundamental pathophysiology is not completely understood yet, but the available evidence implicates the accumulation of abnormal proteins into microscopic aggregates in the brain. These aggregates form from proteins that are present in the normal brain but are processed by the cells in such a way that they stick together and over the course of years form solid insoluble structures. These aggregates increase in number over time, disrupting the connections between, and eventually killing, neurons, irreversibly decreasing the brain’s functional capacity. One of the principle proteins, beta-amyloid, forms plaques on the outside of neurons. The plaques are composed of fragments of smaller precursor proteins that are cleaved from the cell’s surface. The growing plaques then disrupt the connections between neurons, and damage the cells at the same time. The other major protein is called tau, and it accumulates as microscopic tangles of threadlike structures inside of the neurons, disrupting the internal function of the cell, until it succumbs altogether. These aggregates begin forming in the medial temporal lobes, in and around the hippocampi, the structures responsible for forming new memories. At this stage, symptoms may be subtle, such as frequently misplacing objects, exhibiting poor judgment or minor changes in personality. As time progresses, more and more areas of cerebral cortex are involved and the symptoms become more pronounced. The ability to form new memories deteriorates, as does the capacity for thinking and reasoning. Anterograde amnesia, the inability to form new memories, dominates the early phases of Alzheimer’s disease. Later in the illness, a retrograde amnesia develops, whereby the most recently formed long-term memories fade away. The details of autobiographical memories – names, places, events – recede as the disease advances. In the final stages, the ability to

as the audience would theoretically be waning from the deluge of medical information, the vocal track begins to build on itself, repeat, and become interspersed with static white noise. This audio manipulation parallels the mental confusion experienced by those with Alzheimer's dementia. While the track is getting increasingly more jumbled, the amount of movement and chain manipulation by the dancers increases.

In creating the movement for the prelude, I gave the dancers five options of activities. They could simply walk, either in front of or behind the chain; they could stop and look at the audience, inviting intimacy. The other two options mimicked both a normal brain activity and a dementia brain characteristic. At any time, a dancer could "fire an action potential," grabbing and tracing along one string, simulating a typical neuronal impulse. When one dancer did this, each of the others had to do a movement in response, responding to the neuronal activity. Conversely, at any time, a dancer could firmly grip the chain at any point in its network; this action would stop all of the other movers in their tracks. No one was to move until everyone had stopped moving, mimicking the Alzheimer's plaques ability to slow and stop normal neuronal activity.

This prelude serves a multitude of purposes. It introduces the audience to the network as a malleable object, rather than a static set piece. The audio establishes the informative tone of the work, but its manipulation emphasizes the artistic translation of this information rather than a simple regurgitation. The movement that the dancers introduce throughout the prelude gives the audience a physical vocabulary from

respond to the environment dissipates as even swallowing and basic movements of daily life become impossible" (Matthew Schneiderjan, Personal Interview, 20 Oct. 2013).

which to understand the work. Finally, an intimacy is developed between the dancers and the audience that is necessary to deliver complex material.

With the start of the music, a classical piece, Where's My Bow, by Yo-Yo Ma, Stuart Duncan, Chris Thile, and Edgar Meyer, the dance begins in earnest. The first phrase, named "Chocolate" is performed by the quartet in unison. While this phrase, in the performance, mainly serves as a jumping-off point movement-wise, its creation in the studio is what anchored the dancers in the content of the piece. In one of the first rehearsals, I asked each dancer to write down the ten most common things (objects, actions, locations) that they encounter in their daily life. The dancers created a gesture for each of these words, which we used throughout the rehearsal process for phrase generation. To create "Chocolate," I strung together a random assortment of the words to create a group phrase. The intention of this phrase was to give the dancers a solid sequence that they were familiar with, both thematically and physically, that would later be manipulated. This manipulation of what is most familiar, most common, echoes the slow changes that accumulate in an Alzheimer's brain.

In the following transition to Rachel and Stellar's duet, a few things occur on stage. A traveling phrase is introduced, which the duo use to transition to their duet. Jonathan crosses the stage linearly, reiterating the neuronal lines "fired" in the prelude. Most importantly, Chloe re-enters the stage to perform the first chain network manipulation in the actual piece. She takes apart the first of two connection points in the chain, opening up a large portion of the proscenium to the audience. After this audible breakage, Chloe sits to watch the duet.

Rachel and Stellar's duet reflects on plaque accumulation in the Alzheimer's brain. Using movement from "Chocolate," Stellar acts as the plaque on Rachel, interacting with her, changing and hindering her movement. This topic will be repeated in a more dramatic and debilitating fashion later in the piece; this instance is introducing the concept. Its subtlety reiterates the slow onset of Alzheimer's dementia – there is not a great change all at once, but steady degeneration over time.

After a transition with all four dancers, Rachel begins her "brain map solo." I gave her an image of a typical MRI of an advanced Alzheimer's-inflicted patient and asked her to study it. In this solo, Rachel traces the map with a pointed finger, detailing the intricacies of the brain and the gaps left by nonfunctioning neurons. While this is extremely abstracted for the audience, the impact on the piece came from the dancers studying the map in rehearsal, understanding the global nature of the disease.

The end of this solo indicates a transition in the music, and Stellar starts a linear "firing" of movement across the stage. Towards the end of the phrase, she slows down, stops moving, and is picked up and brought back to her starting place, along the same line, by Jonathan, where she re-starts her solo in earnest. This begins a section of the piece that contrasts nonfunctional and functional neurons. This serves an important message in the work about the nature of Alzheimer's disease. Because of the unapproachable nature of most severely afflicted patients, the general public treats them as if there is very little going on in their brain. This is, as the work tries to demonstrate, not the case. While the parts of the brain needed for proper communication and correct social actions are impaired, there is so much neuronal

activity going on. I chose to contrast these “dead” sections and the still active sections to display this theme.

In this section, there are times when Chloe is nonfunctional, being dragged, while Jonathan is sharing the stage in an extremely active state. Stellar’s solo reflects on both a “dead” neuron and a still active one. When the quartet is on stage in this section, the movement is complex, and its derivation focused of the pathological changes in the disease. Rachel’s work in this section is representative of a movement exercise that we did often in rehearsal that manifests itself in transitions, this section, and at the end of the piece. In this exercise, I asked them to take the original “common” gestures and only do half, or a quarter, of each gesture – and then stop and stand – in quick succession. They had to stop each gesture at an exact point through its enactment – unable to fully complete the task. This is reflective of the loss of ability to accomplish many daily tasks in an Alzheimer’s patient. In Rachel’s solo here, she enacts her full 10-gesture phrase followed immediately by her half-gesture phrase, remarking on the degeneration. This loss of ability also simulated by Jonathan’s solo, where he transitions from full, active movement to the same moves, but hindered by the fact that he must be sitting. All of his familiar movement was forced into unfamiliar territory. Simultaneously, Chloe and Stellar cross the stage, again linearly, with the traveling phrase previously introduced. While Chloe is functioning, and doing the phrase, fully, Stellar is doing the “mutated” phrase. To create this phrase, I applied the direct genetic mutations that result in the formation of Alzheimer’s plaques to the components of the phrase. By making each movement an “amino acid,” I gave Stellar similar tasks to manipulate the movement as would

happen to these amino acids in these plaques. This resulted in inversion, duplication, lengthening, and transforming of movements that mirrored molecular mutations like a conversion of an acidic to a basic amino acid, or the insertion of a new base.

Rachel abolishing the second chain connection in the neural network served as the transition to the final section. In this section, the accumulation of plaques was enacted in earnest, as Jonathan as the neuron in question and the other three dancers as plaques. As each dancer accumulated on Jonathan, his movement was more and more hindered until he was still altogether. In the final minutes of the piece, each dancer takes on a different aspect of the information that I was trying to translate through the work. Rachel re-performs her brain map, reiterating the global complex nature of the disease. Jonathan does a classic degeneration of gestures phrase, emphasizing loss of familiar abilities. Chloe is similarly impaired, only doing snippets of movement on the ground. Stellar is the only one moving around the stage, always linearly, and continuing to manipulate the chain and reflected on the prelude. She is “firing,” reminding the audience that there is still immense psychological activity in the Alzheimer’s brain despite all of the degeneration that has occurred on stage for the last ten minutes.

Attachment Behavior (2014)

The initial concept for *Attachment Behavior* was based on maps. I had encountered maps in many aspects of my dance and illness experiences leading up to this research, in many forms. In my research for *Cement*, I studied both molecular genetic maps to understand some of the protein mutations behind Alzheimer’s and

MRI brain maps to visualize the brain damage caused by the disease. In modern dance and choreography classes, we had learned the technique of “mapping” across the space – this mapping could be of one’s life, an experience, or an event. Mapping seemed particularly applicable to Alzheimer’s disease, in which the pathology causes one to often lose track of their thoughts, actions, or desires at any given time. Maps serve the function of guiding someone to where they want to go or what they want to do.

I began rehearsals for the work on February 1st, 2014. During the first rehearsal, I had the dancers, including myself, draw a map of their day. I gave no further instructions or definitions of what a “map” should be. It was a simple task, and straightforward interpretations of each of our days – lines tracing paths walked across campus, drawings of activities, or of thoughts. From this map we began building movement material. The dancers described the maps in words, created phrases with these words, and traced their maps in the rehearsal space. These materials were to serve as the building blocks for an experiential loss of memory. For the next six rehearsals, which took place over the course of a few weeks, we re-drew our maps of February 1st. Each time we drew the maps, the day had become more and more blurry in our memories, and the maps subsequently became more abstracted. Consequently, movement changed and morphed throughout its creation based on what the dancers remembered and what we did not.

Two Alzheimer’s characteristics served as the movement manipulation structures for the work: impression imprinting and the titular attachment behavior. By the information-processing view of memory, “information from the outside is first

taken in as an impression, then imprinted into memory before it can be retrieved for expression or recalled as a memory.”⁸⁵ In persons with Alzheimer’s dementia, the number of impressions created progressively decreases, as well as the number of imprints made of those impressions. I translated this process to the map-making and recall exercise I exacted with the dancers during every rehearsal, to interesting results. Some of the dancers memories of the day disappeared to the point in which the dancer gave up trying to remember all together, and just simply drew chaos. Others were able to remember only the parts about their day that they had spent with other dancers in the piece, thereby “recognizing” the event rather than “recalling” it, another phenomenon described by Miesen that occurs in persons with dementia.⁸⁶ These issues led to various translations of a movement sequence by each of the dancers.

Belé Miesen’s attachment behavior theory⁸⁷ relies on the fact that persons with Alzheimer’s dementia react to what they think, feel, and experience. With memory-impairment issues, like decreased impression imprinting, those with dementia are likely to seek safety in others close to them. This “closeness/proximity-seeking behavior” defined as attachment behavior by Miesen. All people, regardless of illness, demonstrate this type of behavior at times, when under shock, in a disaster even, or with abrupt movement or action. Therefore, in conjunction with memory impairment, it is logical that persons with dementia would demonstrate this behavior often; with little to no memory of events taking place, many actions or movements in

⁸⁵ Bère M. L Meisen, *Dementia in Close-Up*, (New York: Routledge, 1998) 34.

⁸⁶ Miesen theory states “remembering information is easier with it is ‘recognized’ from information presented to you, than if you have to ‘recall’ it without help” (Meisen, 52).

⁸⁷ Miesen, 58-81.

that person's environment would seem sudden or illogical, and produce this attachment behavior. I worked with the attachment behavior theory in the putting together and staging of the movement material.

The piece begins with a prelude of images. The stage has an MRI series of a patient with advanced Alzheimer's dementia and subsequent loss of brain mass in juxtaposition with the images of the maps drawn by the dancers. These two sets of images alternate in rapid succession to the sounds of an MRI machine. I set out to create an introduction to the work that places the audience in an unsettled state, not unlike a very tame version of the altered state of a person with Alzheimer's. From this introduction, the dancers begin to emerge onto stage, performing a gestural series derived from map-based movement material. This material is repeated throughout the piece, in increasingly fractured forms.

The first time that we perform this gestural series, we perform it fully connected, interested, and in tune with our bodies. All of the dancers were able to take this phrase and insert movement, alter the timing, or change their performative focus in order to adapt the phrase to make it personal and fully developed. This enactment of the phrase was a beginning point for the disintegration mimicking the Alzheimer's experience. In the subsequent enactments of the phrase, the dancers begin to take on a more mechanic performativity, representing disconnect between the mind and body that develops with dementia. As the body would start to disintegrate, second to the memory and mind, the dancers begin to fracture the phrase, performing only "halves" of movements and appearing unable to fully enact the movement.

Throughout the piece, interspersed with the material degeneration portraying the loss of impression imprinting, there began an accumulation of “attachments.” The dancers would make physical connections with each other onstage when they had forgotten the next move or had been “unable” to perform a movement fully. These sudden and intense connections to each other were indicative of a need to find something familiar whilst experiencing a sense of confusion like that of Miesen’s attachment behavior theory.

The ability to form these attachments was the primary focus in my casting of the piece. My dancers – Caroline, Chloe, Hibiki, Maya, Nora, Rachel, and Stellar – were all chosen because of their relationships to one another. In the attachment behavior theory, persons seeking these connections find them in persons that are most familiar to them and provide some sense of comfort.⁸⁸ Each of the dancers above had personal relationships with each other, ensuring that the connections on stage would not feel contrived. Additionally, I chose to participate in the creation of the piece as a dancer as well as a choreographer, making myself experience the degeneration alongside my dancers. I believe that because the formation and manipulation of the movement was based on experience, I would not be able to honestly give tasks to my dancers without becoming one myself.

These attachments create the various sections of the piece. The connections begin very physically. Chloe and Caroline are the first dancers to form a relationship; they perform a duet that sets off a series of duets between the rests of the dancers. These duets maintain strong, intact movement while developing the connections

⁸⁸ Meisen, 59.

between the partners. At the end of these duets, the attachments become physical for the first time, with one partner grabbing the other's wrist. This mimics the hand-holding connection that those with Alzheimer's often seek when confused or startled.⁸⁹

As the piece continues and the movement breaks down further, these connections become less dance-oriented and more focused on pure physical and visual connection with another dancer. However, there are times in the piece, or in the dementia experience, where there is not another person to connect with or relate to. In *Attachment Behavior*, I tried to create a movement that would signify this sense of confusion or loss when another person was not there to alleviate it. This led to the gesture that is sprinkled throughout the piece and also concludes it. The gesture involves arms thrown up with a sense of desperation and subsequent "searching" around the space and around the body.

The audio serves as the final contributor to the overall setting of the work, which along with the introduction, dancing, and lighting, places the audience in a thoughtful and unsettled mindset to watch the piece. *Attachment Behavior's* soundtrack is a mosaic of MRI machine sounds, Steve Reich's jarring "Different Trains" movements I and III, Alanna Shaikh's TEDTalk "How I'm preparing to get Alzheimer's",⁹⁰ and recordings of the dancers. At the beginning of the semester, I had the dancers record a text - a sentence, poem, song, or phrase - that they thought they would remember forever in the way that my grandmother remembered the Lord's prayer (see Introduction). These recordings are heard throughout the track and are

⁸⁹ Meisen, 58-81.

⁹⁰ Alanna Shaikh, "How I'm preparing to get Alzheimer's," TEDTalks Jun. 2012.

layered with increasing complexity. This addition created an interesting juxtaposition, as noticed by my dancer Chloe, which seems to encompass what I discovered about dancing the ill body for the last year.

Conclusions

“When I performed the piece, I felt as if I was caught in the act of remembering and forgetting. The dancing was itself remembering and forgetting. When we did ‘halves,’ stopping in between each move to look off stage, I had to actually think what comes next? And I found I always forgot something, every time we performed, no matter how comfortable I felt with the material. This forgetting was juxtaposed with the sound score, which incorporated the ‘texts’ we think we’ll remember forever.”
Chloe Jones, dancer

In both *Cement* and *Attachment Behavior*, I had created two goals for my choreographic research: give my dancers an intimate understanding of the complexities behind Alzheimer’s Disease through the rehearsal process and translate some of this knowledge to an audience through performance. The success of both of these objectives can be gleaned from Chloe’s description of her experience above. The dancers did not simply learn or understand the acts of “remembering and forgetting,” so engrained in the Alzheimer’s dementia experience, but actually “felt” and performed them. The work was able to develop the dancers’ intimacies with the Alzheimer’s disease progression. Additionally, the way that the works were performed, like the juxtaposition of forgetting and “remembered” texts in *Attachment Behavior*, or the chain network in *Cement*, created powerful images on stage to affect the audience. It was only through the complete embodiment of this material that the dancers were able to understand and perform with such knowledge and power.

Performing the ill body through the vessel of a well body allows for the exploration of illness, memory, and embodiment in a richer way than would be possible through traditional research. One's body is the most personal object one possesses. The dancer places further importance on the physical body, commanding it as their artistic, athletic, and creative vessel. It is difficult to imagine the importance of that body when its actions and abilities are so subconsciously engrained in our daily, healthy lives. When the dancer performs as an ill or disabled body, they advance their own understanding of the body. Through movement, dancers like Chloe are able to actually experience some of these disease processes rather than just learn about them – this embodiment of the processes is the ultimate understanding.

Conclusion

Embodiment as the Ultimate Tool

“[With dance,] you have chosen to use your body, to add to your body, to gesture with your body in ways that both challenge how your body can and should exist in that world but also become complicit with certain understandings of it.” Thelma Golden⁹¹

The common thread running through the works of Bill T. Jones, the Dance for PD program, and Alzheimer’s choreography is the importance of embodiment. When confronted with an illness like HIV/AIDS, Jones strove to empower that bodily “betrayal” through embodied performance. The Dance for PD dancers have used movement embodiment as a way of separating from the ill Parkinsonian body. Finally, my dancers, through embodiment of Alzheimer’s Disease, gained an experiential understanding of the ill body.

Dance embodiment fulfills two goals: the creation and maintenance of a new creative, performative body, and the minimization or objection to the stigmas associated with illness. Dance serves to realize Arthur Kleinman’s objectives: “To understand how symptoms and illnesses have meaning, therefore, we first must understand normative conceptions of the body in relation to the self and the world.”⁹² This creation of a new dancing body removes a person, at least partially or temporarily, from their ill body, thereby yielding a new relationship between one’s body and self. Dance of an illness, or with an illness, produces a new perception of disease for the well world through dance’s insistence on agility, flexibility, performativity and complexity – features not usually associated with disease.

⁹¹ “Bill T. Jones,” *Art Performs Life: Merce Cunningham, Meredith Monk, Bill T. Jones*, Ed. Kellie Jones, (Minneapolis, Mn.: Walker Art Center, 1998) 128.

⁹² Kleinman, 13.

Bill T. Jones approaches this relationship to the well world with great persistence. His dance presses “on the productivities of what bodies can be and do while refusing the victimology and moral panic that insisted that some need be forgotten and left behind.”⁹³ Jones uses dance and performance to both establish his own bodily productivity as well as raise consciousness of the productivity of the generalized ill body. Jones’s work insists on a strong, complete picture of the body despite convictions of what that body should be in relation to its illness.

The Dance for PD program emphasizes the body’s relation to the self in its establishment of a new dancing body in persons with PD. With so much energy focused on one’s illness and its consequences, the body becomes consumed with its fallibility. Dance allows for embodiment of an entirely separate body – one that does not exist inside hospitals or with doctors and medicine – while also serving to heal, in perhaps inconspicuous or unintentional ways, the ill body.

Embodiment is the answer to Kleinman’s call to “understand how symptoms and illnesses have meaning.” A diagnosis can radically alter one’s perception of the self and of one’s place in the cultural and societal landscape, but so can dance. The dancing body reinstates power, dignity, and self-awareness to an ill body. Performance and movement, whether at a professional, amateur, or academic level, enhances one’s understanding of health, loss, and consequences; they allow one to surpass a superficial knowledge of these topics to a deep connection with the body and self. At the intersection of dance and illness, embodiment is the ultimate form of reconnection.

⁹³ Martin, R., 77.

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