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Feeling Lovely: An Examination of the Value of Beauty for People Dancing with Parkinson's

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Sipping tea in Carroll's flat, we began the interview. Carroll immediately exclaimed: "The dance class really changed my life. I am much more positive. It's something about the music, rhythm and ballet, which makes you feel lovely. I haven't felt lovely in a long time. This disease is grotesque" (Carroll, March 13, 2012). Carroll has Parkinson's. It is a neurodegenerative condition that affects voluntary movement and balance, and is characterized by tremor, muscular rigidity, and slowness of movement.[1] I was intrigued by Carroll's comment, and how passionately she articulated it. The ramification of her feeling amplifies a number of issues in thinking about dancing, disability, and beauty. In particular, her comment allows us to rethink of the place of beauty within a community dance context and in relation to a chronic degenerative condition. In harnessing post-critical readings in both aesthetics and sociology of illness, I start to address some of the concerns laid out previously (Houston 2011) on how to engage through research with the dancing person, rather than the medical patient, and how he or she might ascribe value to dance as art or as a social practice, while dealing with a degenerating and potentially life-changing condition.

The boundaries between disability, illness, and wellness are blurred when considering a degenerative condition, such as Parkinson's. Many people with Parkinson's do not consider themselves disabled, or even ill, and yet many suffer social indignities and barriers to social participation because of their condition. Others articulate the frustration and vulnerability felt when having to deal with unpredictable symptoms that, in their view, rob them of a feeling of wellness or of what they consider as normality. Some feel gratified that they feel healthy. Many experience all of these feelings and viewpoints at different times in their lives with the condition, which typically manifests after the age of fifty.

Carroll takes part in a dance class tailored for people with Parkinson's in London, which is led by the large-scale repertory company, English National Ballet (see Photos 1a and 1b). Dance for people with Parkinson's is growing in popularity, and many find enjoyment, solidarity, and even lessening

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Photo 1. Students enjoying the English National Ballet Dance for Parkinson's. Photography by Belinda Lawley.

of some Parkinsonian symptoms. It is an activity that has gained prominence through internationally recognized dance programs, such as that run by Mark Morris Dance Group, Dance for PD, from New York, and through regional initiatives, such as that run by English National Ballet, as well as through the blogosphere [see for example Kelsall (2013) and Dawson (2007)].

The dance class that Carroll and approximately forty others attend is led by specialist teaching artists who deliver an inclusive dance class based on the principles of ballet and movement differentiation, with music from English National Ballet's repertoire, including works such as *The Rite of Spring*, *Romeo & Juliet*, and *Sleeping Beauty*. Improvisation is included within the sessions. The class starts seated and progresses to standing, then moving across the studio. Although ballet "steps" are not normally used (the arabesque, the pirouette), there is an emphasis on lengthening the spine and limbs, projecting energy through eye focus and enlarged kinesphere, and changing dynamics and qualities of movement. Despite working within the ballet oeuvre, the sessions are not concerned with constricting the movement vocabulary to the ballet lexicon, or with how movements are executed. Indeed, individual ways of moving are celebrated. Music plays an important part, with two musicians improvising around the ballet score, and the improvisatory approach to music mirrors the open attitude to the movement. The teaching artists define their leadership through a person-centered approach by focusing the class on the abilities that people have, acknowledging and witnessing individual contributions.

The phenomenon of dance for people with Parkinson's is gaining some interest within the academic community, which has given the activity some credibility as a "suitable" pastime for that population. The main focus of study, through clinical measurement, has been the functional control given to participants while dancing (Batson 2010; Duncan and Earhart 2012; Hackney and Earhart 2009, 2010; Hackney, Kantorovich, and Earhart 2007; Heiberger et al. 2011; Marchant, Sylvester, and Earhart 2010; Volpe, Signorini, Marchetto, Lynch, and Morris 2013). Dancing to music with a defined pulse has enabled many with Parkinson's to regulate their gait, causing movement to flow more easily (Houston and McGill 2013). This regulation of gait can give rise to feeling the rhythm and flow in movement, adding to a general sense of feeling capable. Parkinson's blocks people's ability to recall how to do things, but it does not take that ability away entirely (Sacks 1991).[2] Encouraging participants to move with different qualities and offering them visual, auditory, or kinesthetic cues, such as music, imagery, and a movement structure, enables them to move in a freer fashion and can promote feelings of competence and confidence (Houston and McGill 2013). Parkinson's can draw people inward: the gaze may become fixed, arms and legs stay close to the body as muscles become tense and slow. The ballet class emphasizes projection, enlargement,[3] and changing qualities of movement. With these emphases, dancers may experience a different sensation from that which they normally experience and one which they find pleasurable. Most researchers, such as those listed above, are interested in capturing these changes to gait and other motor functions.

Many in the disability arts movement (see for example, Bessing 2008; Silvers 2002) will disagree with the notion that one has to alter one's normal way of moving to feel good, or more confident, or competent in dance. I would agree with this without denying the changes to gait patterns that happen to people with Parkinson's dancing to music and their feelings in relation to this change. The changes that happen are part of the whole experience of Parkinson's, and for the few who dance, these are often moments of, in their words, freedom or beauty.

Conducting a four-year research study on experiences of dancing with Parkinson's led me to the interview with Carroll. The research is a mixed-methods study over four years, using biomechanical and ethnographic ways of researching, partly to triangulate data and partly to extend further the typical methods and topics of inquiry in this field of study. The aim of the study is to understand the participant experience of dancing, whether that involves physiological changes, or emotional, intellectual, and social experiences (Houston and McGill 2013). My specific role within the research team, as well as directing, is to document people's experiences from an ethnographic perspective. By conducting participant-observation and interviews and reading participant diaries, I use grounded theory to understand the following:

- People's responses to dancing
- The relationship between the materially degenerating body and the person creating movement within time and space

- Why dancing might matter
- What contributions to movement as an artistic medium are gained from studying Parkinsonian ways of moving (Houston 2011)

I was struck by Carroll's insistence on the feeling of being beautiful as the most important aspect of participating in the dance class, which did not wholly seem tied to the fact that her movement temporarily becomes more fluid. Carroll returned to the idea of feeling lovely at the end of the interview, stressing its importance for her:

> I've a feeling these classes are going to be my life-line. It's a combination of physical exercise, which is superb, but also for me it's a sense of being beautiful again. I feel so degraded with the disease. It's very, very important to me that my body is doing something pretty again. ... This disease is quixotic and dehumanizing. Ballet brings you back to childhood. I just love it; I really, really love it. (Carroll, March 13, 2012)

Her insistence invites me to query whether the right questions are being asked in research and evaluation studies (such as Hackney et al. 2007; Hackney and Earhart 2009, 2010; Volpe et al. 2013), which tend to concentrate on instrumental effects and physical benefits. Dance is characterized as a possible means to increase physical aptitude, or to counteract Parkinsonian motor symptoms. These potential outcomes are instrumental in showing measurable clinical benefit to the patient.[4] The idea of feeling lovely does not figure in any assessment; even the well-used Parkinson's disease quality of life questionnaire, PDQ-39 (Jenkinson, Fitzpatrick, Peto, Greenhall, and Hyman 1997), does not address the topic of beauty. Yet, the dominance of instrumental benefit in Parkinson's research provokes the question as to whether Carroll's response has to be dismissed as irrelevant because feeling lovely in a dance class is inconsequential to the serious business of curing Parkinson's.

The domain of clinical research into dance for people with Parkinson's is characteristic of a medical conception of Parkinson's and of dance: dance is a means to alleviate symptoms. Indeed, some participants initially are attracted to a dance class because of the possibility (as yet unproven) that it may help slow down the progression of the disease and disablement. This motivation to dance differs from the aims articulated by many dance session leaders that are focused on participants enjoying dance as an art form and as creative endeavor, rather than as therapy. For example, the teacher training manual written for the Mark Morris Dance Group's Dance for PD class explicitly describes that Dance for PD "emphasizes dancing for dancing's sake, rather than focusing on movement as a way to reduce symptoms" and "emphasizes aesthetic objectives, rather than mechanical, clinical, or practical goals" (Dance for PD 2011, 6). Dancing is the aim, rather than therapy as the goal.

The prevailing culture surrounding Parkinson's is dominated by the urge to find a cure. National charities, such as National Parkinson Foundation, Parkinson's UK, Cure Parkinson's, European Parkinson's Disease Association (EPDA), and the Michael J. Fox Foundation for Parkinson's Research all concentrate research funding and much of their fundraising into finding a cure.[5] Parkinson's support groups regularly bring in researchers to talk about the latest advances in the science of Parkinson's, and they enthusiastically support fundraising activities for Parkinson's charities. The dance participants at English National Ballet regularly send me links to the latest research publicity claiming that a cure might be imminent. In my role as a researcher and, so in their eyes, a knowledge-holder, I am asked to respond in helping them divine whether this might be true. The medical culture is strong; it concentrates on investigating why people develop Parkinson's, achieving correct diagnosis of symptoms and effective treatment, and ultimately curing or preventing the disease. When a person with Parkinson's may ingest between two and thirteen different types of medication several times a day in order to control some of the symptoms, it is easy to see why the concept of restitution might dominate lives.

A restitution narrative accepts that in having Parkinson's, there is something wrong or lacking: that "a person is not whole, not really able, unless one is 'cured'" (Stoltzfus and Schumm 2011) and that advances in medical research can fix this lack. Sociologist Arthur Frank (2013) argues that the restitution narrative is seductive in its clean modernist certainty that illness will be converted to wellness, and it is only natural to wish this when taken ill, or after being diagnosed with a neurodegenerative condition. In taking this position, as several high profile Parkinson's charities and scientists do, there remains little to help people address the issue of what constitutes well-being and renewal within life as experienced with a chronic condition (Goering 2002), particularly if there cannot be any restitution. Frank notes that, "The central problem is how to avoid living a life that is diminished, whether by the disease itself or by others' responses to it" (2013, xvi). Critics of the restitution narrative argue that in pinning all hope and authority on the medical professional or researcher, there is less space for other ways of addressing the experience of living with a disease that help the person "reclaim" (Frank 2013, 7) their sense of being a person (rather than a patient) for themselves. The humanity that Carroll seeks from her position of being "dehumanized" is her call to reclaim this for herself.

Carroll's call to reclaim humanity destabilizes the concept that restitution is the only valid narrative for those with Parkinson's. Moreover, Carroll's stance on the importance of feeling lovely also provokes questions about the status of beauty within dance, in the light of 100 years of philosophical and artistic rebellion against the notion (Danto 2003). The "disappearance of beauty" (Danto 2003, 6) in twentieth-century modern art and dance has created another challenge to discussing beauty as a meaningful concept. Modern art highlighted how beauty does not have to be a necessary condition of art, and so it does not become as important in discussion of artistic creation. Indeed, Danto notes that because of this, "beautiful" and "lovely" have become words to exclaim, in the same manner that "nice" has become a bland and innocuous term for something pleasing. Philosopher Elaine Scarry described the situation as a "conversation" that had been "banished" (2000, 57), and cultural commentator John Holden observes the "embarrassment" or contempt conferred upon those who use the term "beauty" (2004, 23).

Similarly, classical ideals of beauty, which are embodied within the principles of classical ballet, have been attacked by dance scholars within the cultural studies tradition. Ballet is the dance form that exemplifies the principles of the mathematical beauty tradition, where order is produced from the relation between parts.[6] Beauty finds form through line, counterpoise, verticality, symmetry, and harmony of elements, as critics and teachers have extolled (see Blasis 1968 [1820], for example). Scholars have pointed out that modern dance has not only problematized ballet's disembodied female roles, such as fairies and enchanted swans, but also the manner of their depiction, through the disruption of line, harmony, and center of gravity (Wolff 1997). Serious modern dance for serious modern women relegated ballet and beauty into the box of fripperies: beauty and ballet are limited to entertainment that is separated from meaningful sociopolitical engagement, as well as philosophical and critical commentary.

In addition, the disability arts movement has done much in recent years to challenge traditional tenets of art, including classical notions of beauty, in order to champion the artistic validity and abilities of disability performers (Garland-Thompson 2002). Sandahl and Auslander argue that disabled artists have challenged "rigid aesthetic conventions" (2005, 4) to break out of the negative and assumed noncreative positions that have been traditionally allocated to them. These challenges from the disability arts movement partly reside in the postmodernist rejection of universal claims of beauty, highlighting the exclusionary discourse of essentialist aesthetic theories (Eisenhauer 2007; Silvers 2002). Anita Silvers writes that "standards of beauty are typically criticized by postmodernists for fortifying patterns of existing power" (2002, 229). By "postmodernists," Silvers outlines François Lyotard's theory of those who "recognize the personal and political harms that totalizing ideas have visited on people who do not fit into or comply with them" (Silvers 2002, 228). Like Frank, Silvers acknowledges the need for disabled people to be valued on their own terms.

Disability commentators argue that not only do dominant aesthetic frameworks marginalize elements of artistic creation that may hold meaning for the creator or spectator, but they also exclude people who may not fit the definition of formal beauty. Participation in Western concert dance forms is rendered inaccessible to many. Their exclusive technical frameworks reject, for example, those who cannot achieve counterpoise, or who may not produce "line" (Benjamin 2002).[7] In other words, beauty as a philosophical and political concept has played its part in denying artistic validity to those who subvert that aesthetic because of who they are.

In a similar fashion to the disability rights movement, the community dance movement has espoused the value of inclusive practices that appreciate an individual's contribution to dancing. Many commentators argue the necessity to step away from external models of worth that impose particular aesthetic presumptions upon community dancers (Bartlett 2008; Lomas 1998). Unlike Sandahl and Auslander's historical portrayal of community arts for disabled people as "charity" (2005, 1) or "therapy" (2005, 6), the community dance movement, particularly in the UK, has sought to champion people dancing as artists irrespective of how they move or what little formal training they have had. Community dance scholar Christine Lomas (1998) argues that this value of dance for all is embedded within delivery methods that acknowledge and celebrate individual ways of moving. Creating dance for and with disabled people happens not out of pity, or even for therapy, but because we need to recognize the significance and worth of all individuals and their wish to dance and to create. Critics of the restitution narrative argue for a space where those affected by chronic illness may tell their own stories away from the technical information proclaimed, prescribed, and inscribed onto their bodies by the medical profession. Likewise, disability and community dance scholarship propounds the view that disabled artists (professional and amateur) need to step beyond traditional notions of the beautiful to gain a powerful, or "authentic" (Lomas 1998), artistic voice for themselves.

The arguments of disability and community dance scholars illustrate the complexity of the notions posed by Carroll's experience, but do nothing to help us understand Carroll's depth of feeling and experience. Carroll has a progressive condition that is gradually altering her relationship to movement, space, and time, as well as what she is able to do and what she feels she cannot. Exclusion from beauty is apparent to Carroll in how she conceives of herself in relation to Parkinson's, and yet, she invokes beauty—her life-line and the scourge of many contemporary thinkers—through dancing and participating in a ballet class. The primacy of beauty, or "loveliness," in Carroll's experience of dancing calls into question the idea that beauty has no place within the discourse of community dance and chronic illness.

Despite its unpopularity with many theorists, there have been several publications since the 1990s on beauty (Armstrong 2004; Banes 2000; Beckley and Schapiro 1998; Brand 1999, 2000; Danto 2003; DeFrantz 2005; Eco 2004; Scarry 2000; Thompson 2009; Winston 2007; Wolff 2006). Many of these authors have rejected the old Enlightenment constraints on formal beauty and have bypassed postmodern disdain in order to embrace new ideas of what beauty might be. Janet Wolff (2006) states that there is a case to be made for the return to beauty. She and others, such as Elaine Scarry (2000), argue that beauty offers a space for contemplation, reflection, and critique: In the words of Kathleen Higgins, beauty "encourages a perspective from which our ordinary priorities are up for grabs" (Higgins, 1996, 283). Or, as Scarry poetically puts it, beautiful moments act "like small tears in the surface of the world that pull us through to some vaster space … or they lift us … letting the ground rotate beneath us several inches, so that when we land we find we are standing in a different relation to the world than we were a moment before" (2000, 112). In linking altered perspective with embodied feeling, the aesthetics of the beautiful have the potential to draw up new lines of thought and new approaches to situations. Once removed from its association with the hierarchy of analytic aesthetic principles, it is possible to use beauty within its specific artistic, cultural, or environmental context as a way of talking about fairness and justice (Scarry 2000), social action (DeFrantz 2005), suffering (Thompson 2009), and community values (Wolff 2006). As

Wolff points out, social and ideological interests and contexts are implicit in any discussion of the intrinsic value of beautiful art, and these are made explicit within this new "post-critical" discourse. The old critique of beauty as amoral or as an anesthetic to political action is dismissed. Wolff states: "Making the case for a return to beauty means, among other things, re-thinking the assumption that political art is obliged to disrupt aesthetic pleasure" (2006, 146). And, in light of Carroll's situation, making the case for the return to beauty means rethinking the assumption that aesthetic pleasure may disrupt any serious consideration of identity and affirmation of humanity.

The return to beauty for some scholars (DeFrantz 2005; Thompson 2009; Wolff 2006) has involved arguing for a "principled" beauty (Wolff 2006) that deals with beauty as value, without seeking to universalize: "Rather than defending absolute or essential moralities and political values, post-critical thought focuses on the emergence and development of shared discourses of value in the context of community . . . [and] inter-community dialogue" (Wolff 2006, 151). Values, such as beauty, are negotiated and developed within a specific context and are seen within the dynamic relationship between thought, action, and social structure. Beauty through art can become a vehicle for highlighting issues within a shared context. In this way, groups that are marginalized from traditional discourses of beauty may articulate their aesthetic priorities, and through these discussions beauty becomes "a potent and important paradigm for group awareness and well-being" (DeFrantz 2005, 100). As Wolff comments, this "post-critical" stance is formed through listening to the shared articulations of value within a "concept of community" or communities (2006, 151). For example, Thomas DeFrantz (2005) has been able to articulate the value of African American dance through taking into account the social and political interests at the heart of an "Africanist beauty" as a frame to analyze dance works. James Thompson (2009) uses the context of suffering and violence in war-torn communities to articulate the value of beauty in participatory theatre as a source of revitalization and hope.

Making sense of Carroll's passionate affirmation of feeling lovely involves pursuing the value placed on beauty within Carroll's own situation and as part of a shared understanding within the dance group. In so doing, such an analysis may highlight issues pertinent to the link between aesthetics and health, illness and wellbeing.

Carroll has had Parkinson's for seven years but is still in the early stages of disease progression. Despite this, she characterizes her condition as "dehumanizing." In another aside, she calls it "disgusting and horrible" (Carroll, March 13, 2012). The walls in her sitting room are covered with pictures, including those of her younger, charismatic self: actress, mother, and lawyer, and of her late husband in his role as a politician. Dancing between these photographs is the image of beauty, of power, and of family life mixed with living in the public eye. Although still active in charity work, Carroll makes it clear that Parkinson's has created a different feeling about herself and about her body from the image created by the pictures on her wall. As Frank (2013) notes, it is those who develop chronic illness later in life who often find it the hardest to adjust to living with a life-altering condition.

Moreover, since Parkinson's is a condition that gradually progresses, with a bewildering array of symptoms that change through time, it is often difficult for people to come to terms with the disease. Swain and French (2000) point out that even if one tries to eliminate social barriers for people with disabilities, and even with committed championing of disability rights and achievement, individuals may still struggle personally with an impairment or chronic illness. Disability and performance scholar Petra Kuppers discusses this situation in her two-rooted concept of disability: "*Disability* is a slippery word that holds nightshade and sunlight, a concept that grows above ground, in our disability culture politics, and below, in the privacy of the disarticulation of pain, of isolation, of the lived reality of social and physical oppression" (Kuppers 2011, 94). The affirmative and collective expression of disability has to be seen alongside the individual, often voiceless, expression of hurt.

Medical sociologist Michael Bury describes the state of change for a person with chronic illness as "biographical disruption" (1997, 124), whereby his or her sense of identity and control over his or her life is threatened by the onset and progression of disease. Bury identifies two types of concerns, or "meanings" (1997, 124), emanating from biographical disruption for people with specific long-term conditions, such as Parkinson's. The first concern centers on how symptoms may interfere with everyday life and bring a sense of uncertainty to it: "Having Parkinson's makes you insecure because you can't predict what will happen" (Roy February 19, 2011), noted one of Carroll's fellow dancers. Skjalvor (2011, 7) described the condition as "like living with a thief. It controls all my functions, my visual perception, cognition, my mind, blood pressure and body temperature and my sex life. Like a thief in the night, it sneaks up on me and my dignity so that I lose my motor skills and power to control."

The second concern focuses on the symbolic significance of the disease to the person with the condition. In addition to dealing with specific symptoms that may have consequences, such as not being able to get dressed by oneself or not being able to write, the person has to deal with the assumptions, prejudice, expectations, and roles that social discourse confers upon someone with a named condition. For example, one of Carroll's fellow dancers commented on how she was "afraid to be in touch with normal people. I am afraid of being patronized," she said (Zofia, January 13, 2012). Another noted how he sat on his own at parties, finding it difficult to talk (John, January 20, 2012), and Eddie, who at one time was a triathlete, spoke of his gradual isolation from his group of sporty friends "who dropped by the wayside" as his Parkinson's developed (Eddie, January 5, 2012). The EPDA published a number of members' letters, in which a woman named Hanna wrote about a common problem with people misinterpreting the cause of imbalanced movement and slurred words: "To wear a badge that says 'I am not drunk, I have Parkinson's' would be a good idea" (Hanna 2011, 28). Jorge wrote of his own social anxieties in the face of the manifestations of his condition:

> I was invited to an official dinner. . . . The pressure to "perform" feels too much and the quick "give-and-take" that is so much part of a normal life is impossible. Parkinson's also makes my voice different and I often speak, involuntarily, in a near whisper. Add to this a face that is empty of expression—the so-called "Parkinson's Mask"—and you have a clear picture of me as "a loser" in such situations. (Jorge 2011, 30)

Isolation, whether self-imposed or involuntary, is a common consequence of the symbolic significance of the disease. The social power of those who can direct social situations through speech or action is a contrast to the marginalization of those who find themselves without voice or movement.

It is here in the meanings attached to biographical disruption that beauty meets Parkinson's and where the symbolic significance of beauty is formulated. Carroll's comments about disgust are typical of many people who have Parkinson's, as is the black humor that colors some of her other comments. It is interesting to note that scholars and artists have articulated understanding of disgust by pitching it deliberately against beauty (Danto 2003). As with beauty, disgust owes much to morality and social etiquette (Miller 1997). As a moral and social concept that raises beauty on a par with goodness and social worth, disgust at the same time identifies itself with a lack of beauty and social value. Self-disgust links to embarrassment, a common sufferance for those with Parkinson's, who, as pointed out above, sometimes socially isolate themselves in order to hide the signs of bodily disorder, or who find the reaction of others difficult to bear. The loss of control over one's body may stand, in Carroll's eyes, for example, as an embodied symbol of anti-beauty.

A key element of social acceptance is to have control over one's actions. Ann Cooper Albright (1997) notes that, because of this, the disabled body becomes a symbol of the uncontrolled and "grotesque" (1997, 74). As a result, some disabled people experience prejudice. In particular, Albright notes that concert dance, such as ballet, is associated with hiding pain, sweat, and effort—the elements that highlight the struggle with controlling one's body. It is no accident that classical ballet and other dance forms that privilege control are associated with an aesthetic of the beautiful. Telroy Davies (2010) suggests that in order to counteract dance's collusion in this cultural phobia of uncontrollability, it is necessary to look anew at movement that dancers with impairments or chronic conditions may offer, that it can be seen as "unique, unprecedented and valuable" (Davies 2010, 61), and to acknowledge that we all have to "negotiate with our bodies" in order to perform movement (61). Davies suggests that this way of thinking allows those who are struggling to reconnect with dance and to live well with a chronic condition, to see themselves as artists, rather than as objects of medical scrutiny and sympathy.

The concept of biographical disruption fits well with Davies's argument. The loss of control felt at the height of biographical disruption may be approached differently through a re-evaluation of one's life with disease, where biographical identity reasserts itself, albeit in a new way. Frank (2013), himself in remission from cancer, argues similarly. He uses the term "chaos" to describe the periods of panic and powerlessness that can be felt by someone who develops a disability. This chaos is contained through a different way of thinking: thinking about how one *lives* with the condition and connects with others, about how possibility in life can be created. Frank terms this attitude and process of discovery as a quest narrative:

> Time spent being ill ceased to be time taken away from my life. Instead, how I lived with illness became a measure of how well I could craft a life, whether I was ill or healthy. This attitude is the basis of understanding one's story as a quest narrative. Illness remains a nightmare in many ways, but it also becomes a possibility, especially for a more intimate level of connection with others. (2013, xv)

Within a quest narrative, dance can become a tool to help with the crafting of possibilities. Thompson (2009) examines the link between participatory art, beauty, and renewal in his work in war-torn communities. He suggests that seeking out beauty may counteract pain. Local artists that he interviewed in war zones (where violence, pain, and disability are commonplace) cried out not for "a 'theater of atrocity'" in order to reflect experiences of hurt and hopelessness "but for a 'theater of beauty'" (Thompson 2009, 138) in order to awaken possibilities. A theater of beauty dwells not on the frustrations, isolation, pain, and disability many people with Parkinson's experience daily, although they are there and acknowledged through the extra work put in by the teaching artists.[8] Instead, a theater of beauty focuses on participants' abilities, creative explorations, and communal endeavors that they may not have had the chance or the courage to experience very often since the onset and progression of their condition.

A theatre (or dance) of beauty is "enlivening rather than depreciating" (Silvers 2002). In the instance of dance for people with Parkinson's, the focus is on moving, creativity, artistic interpretation, and social interaction, not on disease and disability. With this focus in mind, one may appreciate participants' unique ways of moving without resorting to pity or charity, and participants may value dancing for the shared experience of moving with beauty, not just for its potential for exercise. In this way, one may appreciate that Parkinsonian movement expands the notion of what dance can be, just as dance for people with Parkinson's may expand the notion of what beauty can be. Silvers (2002) argues that such an enlivening perspective of art and beauty gives meaning to the diversity of the human condition and, so, I will add, to Parkinson's. Parkinson's is still a fact of life for one in 500 of us, and, as our population ages, this figure is set to rise (Parkinson's UK 2013).[9] As Carroll's case hints, dance may contribute to people with Parkinson's valuing what they can create through movement, even though Parkinsonian movement has many negative connotations and consequences.

Some people with Parkinson's have been able to embark on a process of discovery of the potential in their lives as lived with a chronic condition. Bob Taylor, User Involvement Advisor for Parkinson's UK, decided to change his life and those of others after his diagnosis of Parkinson's. He wrote a story of his quest to me. Within it, he becomes evangelical about thinking differently about developing a disease:

> Learning from my own experiences, I feel that the first thing people want to do when they encounter disease is to put a name on it. However what do you do when you have been labeled: deny it, give in to it, or fight it? The situation is not helped by the fact that friends and family often do not know how to deal with it. Often people's perception of anybody with a serious illness or disability is that he or she has lost something, and frequently they do not know how to communicate because of preconceived notions that they are abnormal.
>
> It is my belief that there is another option; embrace it because it is born of me, and to find the answers that lie within me. Every one of us is unique and our illnesses are individual to us. People who lose something, if they are empowered to take the positives from their "wake up" call, may realize what gifts they have and achieve greatness. They no longer want to be "normal" and moan over what they don't have. Normal means average, routine, standard, ordinary. This is potentially a defining moment in their lives, if they really want to go for it! Their chance to be EXTRAordinary. (Taylor, August 20, 2013)

Taylor's words are echoed in the scholarly argument of Silvers (2002). Her argument centers on how depictions of disability in art and art created by artists with disabilities affirm the diversity of human biology and history. They offer an expanded vision of beauty, which "elevates otherness to originality" (Silvers 2002, 241). This affirmation of diversity and originality makes disability meaningful. Silvers offers the example of Van Gogh: "We apprehend Van Gogh as an original, an amplifier of culture, rather than as a cultural other. So, although disturbing, the extraordinariness of Van Gogh's manner is seen as being meaningful" (2002, 242). She concludes: "Showing that disability is often obscured and undervalued does not suffice to shatter the bonds imposed by routine discourse. . . . We need to shift from repudiating socio-political relations to realigning them by reshaping beauty into a more expansive idea that revitalizes the meaning of disability" (242). Although Silvers talks of great artists and Taylor relates everyday stories, their emphases remain very similar: one may appreciate the diversity of human existence at the same time as valuing the extraordinary within people and art.

Pamela Quinn describes herself as an "outlier" (Quinn 2013, 40), as someone extra-ordinary. After early onset of Parkinson's, Quinn gave up her career as a dancer. Yet she realized that her professional knowledge and understanding of movement was helping her manage the condition in a way that not many others could. [When I interviewed her fifteen years after she was diagnosed, Quinn (2011) commented that she had only just started to take medication.] As a result, she now teaches others with Parkinson's in New York[10] how to use the movement ability they have to greater effect. In the award winning film *With Grace* (Spink, Joshi, and Kraus 2013) danced by Quinn and David Leventhal, Quinn narrates her story as a voiceover. In it she talks about discovering gifts: "This disease is so hard, you say. No doubt. But in a way it gives us more of each other and it bears other unexpected gifts: creativity, empathy, lack of inhibition. What choice do I have to try to accept those gifts with grace?" (Quinn in Spink et al. 2013). In another film, *Welcome to Our World* (Bee 2010), where again Quinn dances and narrates, she cites patience, compassion, and perseverance of spirit as three other gifts that she has received through developing Parkinson's.

The double meaning of "with grace" is evident. Dance has often been twinned with grace, as it has been with beauty, and indeed grace and beauty have often been taken as a pair, along with elegance. [Think of the mythological three dancing Graces, immortalized by Antonio Canova's sculpture, *The*

Three Graces (1814), as an exemplar in point.] The phrase "with grace" becomes more potent as viewers are told that Quinn has Parkinson's, a condition that is seen as taking away graceful movement (although it is noticeable that she dances gracefully). Also, a gift is accepted with grace: grace becomes inextricably linked to the grateful, yet humble and dignified, receiving of a gift. Quinn is aware that this grace is an opportunity to tell her story through her own embodied narration.

Keeping the analogy of the quest narrative, one of the key elements of such a story is often a sharing of a gift (with grace) to fortify the hero or heroine on his or her journey. Quinn has shared her gift as a dancer to help others. As one of her students remarks:

> I feel graceful, which you don't normally do when you have Parkinson's. You're very often clumsy. You walk in a clumsy way and you feel uncomfortable about the way you look or the way others perceive you. And when you're in that class you feel totally graceful. I look around and everyone else is beautiful and graceful too, and it's such a warm and wonderful feeling. (Sharon Resen, in Spink and Kim n.d.)

Sharing in a dance brings the notion of grace to the fore. Watching Carroll improvise with fellow dancer Conrad to the music of Stravinsky's *Firebird*, I first see her eyes sparkle as she focuses on her dancing partner. Then I see her bend to the side and, sustaining the flow of movement, she circles her upper body around to the front and brings her back and head upright. She touches Conrad's elbow, which sharply shifts to the side and his arm unfolds. Lifting his head, he draws a wide arc with his hand in the space to pause above his head. His arm drops gently to touch Carroll's nose. She laughs. He smiles (Fieldnotes, June 30, 2012). The attention to flow of movement, to its changing qualities, as well as to trajectories in space, produces ways of moving that differ from the habitual patterns of everyday actions influenced by Parkinsonian hesitancy, indirection, and boundness.

Fellow dancers Jane and Pat talk about their experience in the same language as Resen, connecting grace, loveliness, and elegance with dancing:

> Pat: I'd say I feel graceful.
> Jane: Yes, graceful and elegant, you do [feel that], when moving that way. So often we do actions clumsily and now you aren't clumsy any more when dancing.
> . . .
> Jane: There are times when you feel definitely not that way. But when you hear the music, there's something in the brain that wakes up and you walk in a different way. The orchestra were playing the waltz just now, and I was coming back from the loo and I found myself moving to a waltz. I was waltzing. Then Danielle held my hand and we waltzed. You just get that feeling of being ...
> Pat: Lovely. Of feeling lovely." (Pat and Jane, January 17, 2013)

It is not important that Pat and Jane might be adhering to well-used vocabulary and long-held beliefs and assumptions that beauty, grace, and dance are intertwined, but that this is what they experience, what they feel is happening to them. Feeling elegant and lovely is not so much a stylistic issue, but a fundamental point relating to identity, self-efficacy, and dignity.

To have dignity and grace implies sharing and witnessing, as seen above in Resen's statement and in the idea of gifts. Contrary to the emphasis in research on dancing as a tool to adjust gait, dancing with Parkinson's is first a social activity, not a solitary exercise regime. Carroll, Pat, and Jane are not dancing alone. They are dancing with others. Conrad moves his elbow when Carroll touches it, Jane holds Danielle's hand to waltz, both move in relation to the other, conversing, smiling. Dancing with beauty is not a totally selfish act. It is not one that entirely orients itself around righting the self because one shares the dancing with others: She laughs. He smiles. What strikes me about Carroll and Conrad's exchange is not the increased fluidity of movement, although as already noted this is important, but the engagement and enjoyment between the two dancers that results in a playful dialogue. In this particular context, feeling lovely develops because people come together.

The joyful sharing of beauty through dance, and through talking about it afterward, bestows communality upon the idea of beauty. A communal experience of beauty is not a universal experience—and those few who felt too overwhelmed by the positive energy of the dance class may testify to this —but it is still a shared experience that is conferred value by participants. So far, only female participants have talked about feeling beautiful—not a surprising outcome given the longstanding cultural link between beauty and femininity. This fact does not invalidate the experience though, which is real and important to those women. Others (male and female) have spoken about the feeling of freedom in the same way.[11] Beauty or freedom in this instance draws people together in a generous desire to share and repeat the experience of dance.

The growing phenomenon of dance for people with Parkinson's is testimony to the urge among adherents that more people with Parkinson's *ought* to experience it. The class Carroll attends doubled in size within the first twelve weeks and doubled again within a year. Over four continents and ten countries, classes are being set up to cope with demand (Dance for PD 2012). The interest from teaching artists is increasing in the UK[12] and in the USA,[13] yet cannot keep up with the demand from people wanting a class local to them. The question of the whereabouts of the nearest class is routinely asked on Parkinson's support group forums and on blogs.

Carroll and Resen experience dance as a way to re-craft or enrich their lives. Dancing becomes a channel for their journey of discovery and reaffirmation of the self and of others. Their dance groups become focal points for them not only to feel good about themselves as individuals (graceful, lovely), but also to feel a sense of group solidarity. They affirm their humanity with others by seeing their dance companions moving gracefully and with beauty, as well as more or less fluidly. Their groups become vehicles for support in living with their condition not because they are about Parkinson's, but because they are about dancing, validating the ability and creativity of a person. In the words of another dance participant, it is dance that "is non-judgmental" (Helena, February 6, 2014). These participants have chosen to take responsibility for their bodies and for what they do with them, despite the loss of motor control. In this way, the dance for Parkinson's initiatives play their part in enacting what Kuppers (2011) calls disability culture. Disability culture is a process that "can suspend a whole slew of rules, try to undo the history of exclusions that many of its members have experienced when they have heard or felt 'you shouldn't be like this'" (Kuppers 2011, 4). Certainly dance has colluded in exclusions of those with Parkinson's and other movement disorders, as well as older people in general, in many Western cultures at least. Indeed, it was only recently that people with Parkinson's were recommended to do any exercise at all. In some quarters, dance has propounded an exclusive beauty aesthetic. People with Parkinson's like Carroll have seized upon their chance to dance to contradict this aesthetic history and have in the process found the gift of feeling lovely.

Taking a stance on beauty that examines how the concept is developed and valued within the context of a dance class for people with Parkinson's throws up issues of living with a chronic condition in later life, as well as what dance may contribute to that life. The place of beauty within the context of a dance class for people with Parkinson's is not a question of judging taste or the veracity of participant comments, but it can emphasize why people may choose to dance despite having movement that has been deemed disordered. In exploring the social contexts in which participants find themselves (or that they create) and understanding why feeling lovely is important to them, it is clear that dance plays a role in helping individuals feel able and loveable. This experience becomes political in the knowledge that people with Parkinson's often do not feel capable and do not feel valued by others, or even by themselves. Dancing is meaningful to Parkinsonian dancers because it gives them a moment of choice, creativity, and responsibility over their bodies. It gives them a sense of freedom in moving and a place where their movement is valued and they are understood.

Michael, a member of the English National Ballet program, wrote in his diary, “dancing like this is helping me to get Mr. Parkinson out of the driving seat of my life” (January 10, 2011). Comments such as this and Carroll’s insistence on the importance of feeling lovely point to an artistic activity that helps restructure biographical disruption away from the uncertainty and symbolic significances that Parkinson’s brings. Feeling lovely can be the result. This outcome may not be measurable, but it is still important to note if dance is to stake its claim as a meaningful social activity. Beauty is not an incidental aesthetic frippery; rather it is important to individuals who value dancing as a key to formulating a different relationship with their disabling condition.

Notes

1. “Parkinson’s” is the term used by people with the condition in the UK instead of “Parkinson’s disease,” and since the research focuses mainly on the UK context, the term “Parkinson’s” will be favored. Parkinson’s affects the ability to initiate or finish movements. Muscles become rigid, and co-ordination difficult. Facial expressions may be masked, and voices may slur and dwindle in volume. Memory recall can be affected, as can the ability to swallow. The characteristic tremor of limbs and kyphosis of the spine are often accompanied by small shuffling steps that results in loss of balance and falls. In addition, people with Parkinson’s often “freeze,” where they feel as if they cannot move even if they would like to. Parkinson’s can provoke social isolation and depression (Cummings 1992). Medication to alleviate some of the symptoms is regularly prescribed, but loses potency after a while and has side effects, such as dyskinesia (involuntary movement). There is no cure, so those with Parkinson’s live with the deteriorating condition for the rest of their lives.

2. The psychologist Oliver Sacks noted in his Parkinsonian encephalitic patients that despite being in a rigid, nonmoving state for most of the day, they would catch a ball thrown to them, and a lady who used to be a pianist would play the piano competently when asked (Sacks 1991).

3. The idea of enlargement is similar to two therapy programs for people with Parkinson’s: the Lee Silverman Voice Treatment (LSVT) Loud and the LSVT BIG. The former is for voice, the latter for movement, where the patient has to concentrate on either speaking loudly or moving in a larger and faster way. The one cue for LSVT BIG is “be big” (Ebersbach et al. 2010).

4. See Belfiore and Bennett (2008) for a critical discussion on the instrumentation of the arts within UK Government policy.

5. Parkinson’s UK would stress, though, that as a charity its remit is much more about helping people live with Parkinson’s, but that its research grant awarding unit focuses on work that will contribute to the development of a cure. EPDA has a similar dual conception.

6. It was the Pythagoreans who laid the groundwork for one of the most enduring, essential theories of beauty (Eco 2004)—one that connects to ideas of proportion, symmetry, and harmony. According to the Ancient Greek mathematicians and those who carried on the tradition through the centuries, these elements were necessary and sufficient conditions for beauty to transpire.

7. Although some dance teaching artists, including the Learning Team at English National Ballet, and artistic directors, such as Wolfgang Stange of the integrated company AMICI Dance Theatre, would argue that it is only the way one uses these frameworks that renders them inaccessible, rather than the techniques themselves. Consisting of older and younger people, those with mental, sensory, and physical disabilities, as well as those with no apparent disability, AMICI takes a weekly ballet class alongside their improvised work.

8. For example, to help with transport to class, to visit hospitalized participants, to telephone people with memory difficulties each week to remind them that the class is on.

9. One in five people over 80 years develops Parkinson’s. It is a disease that largely, but not exclusively, affects older people, so it is clear that as many more people are reaching 100, the probability of developing Parkinson’s is greater.

10. Quinn teaches the Movement Lab at Mark Morris Dance Group in association with the Brooklyn Parkinson Group.

11. The connection between beauty and freedom was made by Immanuel Kant in his *Critique of Judgement* (1952 [1790]) in describing the free play of the imagination in the face of beauty, and his ideas point to a way of exploring the two concepts together, albeit with the challenges to the metanarratives of Enlightenment philosophy in mind.

12. The Dance for Parkinson's UK Network of specialist dance teaching artists was set up in 2011 to bring together teaching artists who had been working in this field for some time, but who felt that they needed more mutual support and opportunities for continuing professional development. The network has nearly doubled in size since it was first formed and now offers training opportunities for dance artists new to the field.

13. The Mark Morris Dance Group Dance for PD program runs regular training weekends throughout the year, and the company gives workshops while on tour internationally. The courses have been running since 2004.

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