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Author

Kane, Krista

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Krista Kane

University of Louisville

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Spinal Cord Injury, “Push Girls” and the Ground Zero of Female Pleasure

I. Woman In A Wheelchair

In 2008, my closest friend, Jane, a longtime teacher and librarian, went outdoors during a terrible windstorm and was struck to the ground by a falling tree limb. The weight of the limb snapped her spinal cord and a protruding branch pierced her skull—she suffered a simultaneous spinal cord injury and traumatic brain injury. Recovery from neural injuries is long and slow—although she may never recover the function she had before the accident, my friend continues to progress five years later. It was in witnessing her treatment, adaptation and recovery that I began to learn what it means to be a woman with a spinal cord injury. The medical aspects of the injury, the rehabilitation and therapy, the dramatic changes in relationships and identity were significant. What I noticed most markedly, though, was the struggle against attitudes and misunderstandings, as Jane disagreed with the limitations and expectations she encountered as a woman in a wheelchair.

With her accident, Jane joined a micro-minority in the population. A group that is too small in number to be considered even a minority. Spinal cord injury, an injury that affects predominantly men, affects women at a ratio of less than one in five.

The special circumstances surrounding women with SCI make their experiences a prime starting point for examining the situation of women with disabilities, their perspectives, their status in the mainstream culture, issues of identity and access, and not least, their attitudes toward, experience of, and right to pleasure.

Neural injury begins with an initial insult, triggering a cascade of damage from the site of the insult through the nervous system as a whole. The secondary aspects of the injury, as the cell damage progresses through the system like cracks through a frozen lake, are more devastating than the first traumatic blow, as nerve cells are marked for inevitable death in a process that is difficult to arrest. The wound is merely the tip of the iceberg, signaling a far greater injury beneath. Mimicking the path of physical injury is the injury to the social being, which is ruptured in its connectedness as the spinal cord is ruptured from its neural connections.

The study of women has long, perhaps always, been complicated by the body. Women's status in their cultures is imagined, determined and dictated by difficult to govern formulae of performance, perception, biology, mythology and anatomy. The category of "disability" further complicates this continuum of identity. We see ample evidence of this complication in U.S. visual culture. Women visibly living with any disability are rarely shown in advertising, television, magazines or films.

I will examine the 2012 reality television series, "Push Girls," as a departure from this lack of representation of women in wheelchairs, probing it through the lenses of feminist psychoanalytic theory and disability theory to better understand whether and in what ways it may act as a new representation of women living with disabilities.

Finally, I will engage Julie Allan and her use of Foucault to frame an "ethics of inclusion," in order to better understand the responsibilities of and actions available to all individuals in furthering recognition and full participation for people living with disabilities.

II. Invisibility

As women are such a small minority of people living with SCI, the majority of the medical

research and medical discourse related to this condition focuses on men. This reality, combined with the relative lack of visible representatives or even representations of this community in the mainstream culture result in social invisibility for women with spinal cord injury. A fact sheet currently available online informs readers that “the effect of SCI on female sexuality is far less devastating than on males,” and also that “the physiological sexual responses for women are mostly internal and less conspicuous than in males and, therefore, more difficult to study.” Further, the same document discounts the accounts of female patients about changes in their own sexuality after injury: “Most of the information that has been reported is subjective (i.e., obtained by history from patients rather than from scientific observation) and is, thus, likely to be less accurate” (Female). This last statement effectively closes off the entire topic of women’s sexuality in SCI, as the physical responses are too difficult to study and subjective accounts are not “scientific.”

Axel Honneth, a philosopher working in critical theory, writes particularly about issues of power and respect in society. After Habermas, he asserts that invisibility is the lack of social recognition, and that recognition is necessary for self-realization. “. . . Recognition possesses a performative character because the expressive responses that accompany it symbolize the practical ways of reacting that are necessary in order to 'do justice' to the person recognized” (114).

Honneth clarifies what he means when he maintains that human beings require recognition. He distinguishes between the German “Erkennen,” which refers to cognition, the apprehending of a person’s presence, in a way that is receptive, and describes the perceiver’s incorporation of the person into a cognitive framework in the perceiver’s own mind. This is in contrast with the vital and subsequent “Anerkennen,” which is productive, referring to the perceiver’s active social

acknowledgement of a person, which serves as affirmation, public recognition.

The experience of living as a woman with spinal cord injury is not given sufficient attention in either the medical or mainstream communities, a reality which equates to lack of recognition. As Honneth asserts, recognition is necessary for self-realization, and the effect of this lack is that women with SCI fall into an uncertain territory of identity (115).

III. Perceptions of Spinal Cord Injury

In order to understand the barriers to recognition for women with spinal cord injuries, it is beneficial to look to phenomenology and psychoanalytic literary theory. Merleau-Ponty theorizes that structures of perception as they relate to the body are shaped by the nature of the body as both body-subject and body-object. “It is by means of such body schemas that we are able to act intentionally in the world, and though they most commonly operate at a pre-reflective level, they constitute our sense of ourselves as corporeal beings” (Lennon). In this way, our human bodies only exist as we perceive them. In understanding the experience of spinal cord injury, it is helpful to incorporate Lakoff and Johnson in their claim that “conceptual structure arises from our sensorimotor experience and the neural structures that give rise to it. The very notion of ‘structure’ in our conceptual system is characterized by such things as image schemas and motor schemas” (77).

Linda Alcoff has explored in *Visible Identities* the ways in which individuals are determined and understood through perceived characteristics of their physical bodies. She writes, “both race and sex ... are most definitely physical, marked on and through the body, lived as a material experience, visible as surface phenomena and determinant of economic and political status” (102). In this way, understanding of one’s identity is based on the ways in which gender and “ability” are reflected in physical characteristics, which are automatically attributed to a

culturally articulated category. The more unstable the category, the more unstable the available (social and subject) identity.

As we examine the language we find in the context of neural injury, physical rehabilitation and paralysis we find illuminated its experiential analog. After the initial trauma of a spinal cord injury, there occurs a “secondary cascade” of effects that worsens the damage exponentially. The online medical reference Medscape describes this, “more commonly, the injury level rises 1 or 2 spinal levels during the hours to days after the initial event. A complex cascade of pathophysiologic events related to free radicals, vasogenic edema, and altered blood flow accounts for this clinical deterioration” (Spinal). “Subjected Bodies,” an essay in *Foucault and the Government of Disability*, suggests a social parallel to this destructive cascade. In this work, Sullivan describes the processes and protocols that are typically used to treat and rehabilitate spinal cord injuries as critical to the “production of a paraplegic.” He describes the way that medical power is directed toward producing a governable, productive body (27). He writes, “recently admitted patients [to a rehabilitation hospital spinal unit] learn very quickly that they have not only lost the power to move and feel their bodies; they have, in addition, lost possession of their bodies, in terms of knowledge and control” (31). Attitudes in the medical establishment toward pain, recovery of function and even the appropriateness of specific types of catheters for urination combine to communicate that a person’s sensations, preferences and identity are under the control of the experts.

IV. Body Parts

A woman with a spinal cord injury is invisible in the medical system, in the sense that she is at once a paralyzed subject, surrendered to the treatment protocols for her injury, and also a null entity as a female with a condition that is gendered “male.” Referring back to the cultural

articulation of identity, Judith Butler writes, “my view in *Bodies that Matter* (1993) was that there is an insistent materiality of the body, but that it never makes itself known or legible outside of the cultural articulation in which it appears” (Breen 12). This suggests that we cannot experience the body, cannot communicate the body, without doing so culturally. In this way, we can sense how a woman with SCI’s own experience is culturally constrained, and that her attitudes, her ambitions and her pleasure become lost, illegible.

In an interview in 2001, Butler discusses the difficulties inherent in gendered identity in the context of transgender individuals,

. . . becoming a gender is a laborious process of becoming naturalized, which requires a differentiation of bodily pleasures and parts on the basis of gendered meanings. Very often what is wanted in terms of pleasure requires an imaginary participation in body parts, either appendages or orifices, that one might not actually possess, or, similarly, pleasure may require imagining an exaggerated or diminished set of parts. (Breen 15)

Butler’s attention to body parts in this passage can relate to identity and gender in disability as well. As she suggests, a person can achieve gender recognition only by occupying a culturally recognizable category. In order for some gender identities to occupy such categories, a measure of imaginary transformation is required to make the “body parts” match the requirements of the category. Not only does a woman with SCI have to demonstrate in the mainstream culture that she can occupy the category of “woman,” with all its ambiguity, but she must also demonstrate that she can occupy the category of *person*, as she inhabits a body living with paralysis. A woman like Jane must defend her performance of both person-ness and woman-ness before she can even reach the possibility of a sexual identity, and for many it is easier just to give up.

There are exceptional rehab centers, physicians, and researchers working on spinal cord injury in the U.S. Among them is Frazier Rehabilitation and Neuroscience Center, where the University of Louisville Department of Neurological Surgery is located. This department is consistently in the top 10 neuroscience departments in the country, as measured by NIH research funding. There is great sensitivity to the needs of people living with disabilities here, as well as a great commitment to furthering paralysis research.

With a couple of noted exceptions, medical experts have paid little attention to female sexual response, sexual self-esteem, and relationships. Significantly, women researchers have been the ones begin moving toward a more holistic study of female sexuality and disabilities. Recent survey and laboratory studies of women with SCI and other disabilities have begun to generate data on sexual self esteem, sexual interest, sexual activity and behavior, and orgasm. One study in particular, at Rutgers, was based on women with complete SCI relaying their “lived experience” of sex and pleasure. The study elucidated that “the ability to communicate sexual needs and desires came with an increasing sense of self and value as a human being. Although the women had regained their sense of identity as people in the world, their sense of sexual identity lagged years [even 15 years post-injury] behind this other sense of self.” (Tepper 620)

Paralyzed women must navigate the same series of identity checkpoints that can paralyze any woman—performing the roles of “person” and “woman,” the acceptability of experiencing sexual pleasure, motherhood—while trying to discern which are the expressions of sexuality, pleasure or agency that might render her invalid and invisible, nullifying previous checkpoints and bringing her back to ground zero, the site of injury.

V. “Push Girls”

The 2012 reality show “Push Girls” was originally billed as the opportunity to “meet four

friends who don't let their wheelchairs define them." The show depicts four women with spinal cord injuries who live in California: Auti, Tiphany, Angela and Mia. The women are beautiful and stylish in the mainstream, runway-model, Hollywood sense, and they have varied careers and relationship statuses. Although some aspects of the show's content are stark in their ability to illustrate some of the real challenges of living with paralysis (such as relying on a romantic partner to help with toileting), some of the others seem less "real" and more typical of some earlier reality-show examples, such as the "Real Housewives" series. The glamour of the group is somewhat suspect, recalling Mattel's 1990s introduction of Becky, a wheelchair-using Barbie doll who was not able to fit into the Dream House elevator.

Rosemarie Garland-Thomson, who theorizes disability, suggests that "women are the proper object of the male gaze, while disabled people are the proper object of the stare" (Lennon). The "Push Girls" representation is complex, and the questions it raises beg the issue of whether viewers are invited to gaze, stare, do both or engage in some entirely separate response. Representations are complicated, in both concept and effect. As Garland-Thomson notes, representation "informs the identity—and often the fate—of real people with extraordinary bodies" (Lennon). So many people with disabilities are economically disadvantaged, and would not accurately be depicted in designer clothing, for example. Whether "Push Girls" will contribute to recognition and social visibility for women with SCI will remain to be judged.

VI. Ethics of Inclusion

Julie Allan engages Foucault as a "philosopher of difference" in the area of practices of the self and transgression. She theorizes around the problems of the special education system in the U.S., using Foucault to problematize issues of power, resistance and desire in this arena. Allan suggests that the facilitation of inclusion requires transformation on the level of the individual in

order to create progress in the system. She maintains that substantive change will depend on “. . . allow[ing] disabled individuals to shape their own identities by subverting the norms which compel them to repeatedly perform as marginal” (27). She posits that individuals must desire change and seek to examine the barriers within their own consciousness that keep them bound to a particular response, for “. . . inclusion starts with ourselves, and that inclusion is not a project that we do to a small group of individuals, but rather, something that we must do to ourselves” (28).

It is clear that the barriers to recognition and full inclusion for women with spinal cord injuries are complex, and that possibilities for change are also complex. The female SCI population is a small, marginalized minority that experiences barriers that are exacerbated by the societal barriers faced by all women. The right to pleasure for these women is eclipsed by the struggle for the right to full representation, but the paths to realizing these rights for all women are intertwined.

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