

Revealed: Performing the Disabled Body with Chronic Illness

Paper Presentation for ASAP/10

October 20, 2018

For this presentation, I've decided to show a recorded video of my performance *Revealed Body* in addition to a power point with images and text that reiterate what I intend to present today. Although we will not be able to listen to the sounds of the video and the sounds of my voice simultaneously, I'm hoping the visuals from the video will provide you with some of the emotional narrative I'm attempting to convey through the presentation.

Bodies with chronic illness may reveal no signs of illness. Bodies with chronic illness endure pain, require maintenance, and cost money. Bodies with chronic illness are both embodied and disembodied. They are bodies in need of technology. Bodies with chronic illness are disabled bodies. Because bodies with chronic illness have invisible disability, their stories are harder to tell through visual art. One way to overcome that barrier is through performance art. Because, performing the disabled body reveals chronic illness in the public sphere, confronts spectators, and calls on others to consider an embodiment different from their own.

For this discussion, I've analyzed two contemporary artists with chronic illness in an effort to broaden our current perspectives and understandings of complex embodiment, or the fullness of the human condition. Through a performative method of analyzing disabled artists Johanna Hedva and Bob Flanagan, I show how these two artists bring their interior, invisible body experience out into the exterior via performance art. Therefore, I ask: How do these artists reveal their illnesses through performance art? How do they make the

invisible visible? In addition, because this discussion uses the Kantian perspective and the study of phenomenology to understand the connection between sensory experience and lived body experience, I also ask: How do these two experiences accumulate into one, and exchange from performer to spectator during a performance?

To not only analyze Hedva and Flanagan but to more fully perceive the lived experience of embodiment before a public, I myself externalized my chronic illness in performance art as is seen here in the video. However, rather than performing the subject in pain, I've exposed the technology meant to fix pain caused by chronic illness in the body by performing my breathing treatment. This brings the technological aspects associated with the private sphere of invisible disability into the public sphere.

In his performances, Flanagan takes a humorist and masochistic approach to revealing his pain due to illness in public space. Hedva, through an auditory approach, covers their face with their hair, makes eerie sounds through slow body movements, and yells common phrases told to people with illness such as "If you reduce your stress, it would help a lot!"

By performing the subject, each artist reveals their interior selves to their exterior selves, while simultaneously exposing their bodies as art objects to spectators. Here, subject can be understood as their disabled, chronically ill bodies. And, their interior selves are synonymous with their bodily experiences, while their exterior selves are synonymous with identity. While both Flanagan and Hedva reveal their bodies as self and as political,

I concentrate on Flanagan as revealing the self and Hedva as revealing the political. In order to explain this more, I use the phenomenological lens of body one, body two, and body three proposed by Don Ihde.

According to Ihde, body one is the sense that “we are our body...in which phenomenology understands our motile, perceptual, and emotive being-in-the-world.” In other words, our body one is how we feel, sense, observe, etc. within and with our body. It is our internal, physical body/self: our organs, lungs, eyes, etc.

Body two is “not biological but socially constructed.” It is the social and cultural sense that we also experience. And, although body two is placed upon us, it is still part of our lived bodily experience.

Body three is “traversing both body one and body two, it is the dimension of the technological.” In other words, body three is how we experience body one and body two through and with technology, where the technological refers to anything that is non-human (something as simple as a pen is seen as technological through this lens).

Although Ihde's phenomenological theory is very useful for organizing the argument and exploring the bodily experiences of artists with chronic illness, his point of view undeniably comes from an able-bodied, Western, cyst-white-male perspective. By placing his theory in connection with a disability studies and art theoretical lens, this discussion extends his theory to other bodily experiences. Ihde is a leading post-phenomenologist, so it is

important that we expand his ideas to include all modes of bodily experiences since we all experience life differently.

So, by positioning Flanagan's performance with Hedva's and then my performance, it becomes clear how each artist reveals their body when seen through Ihde's phenomenological lens: we see how each artist makes their body one visible via their body two. Chronic illness is often seen only in body one, but when seen through performance and Ihde's lens, chronic illness is revealed in body two as well as body three. In other words, chronic illness is revealed from the self to the political with objects and technology.

While these two artists do reveal the interior/private body to the exterior through performance, Hedva and Flanagan both approach their performances through slightly different methods and for slightly different reasons. It is here where my performance became very useful for analyzing and understanding Hedva's and Flanagan's performances through a phenomenological lens and Ihde's explanation of body one, body two, and body three. In fact, each artists' embodiment through performance exemplifies the three separate bodies. Where Flanagan coincides with body one, Hedva corresponds to body two, and I to body three. While these three bodies and three artists are distinct, they work together to create the full body experience.

Bob Flanagan was born in New York, New York, in 1952. When he was diagnosed with cystic fibrosis, doctors encouraged his family to move to an area with less moisture, better

air, and calmer weather. So, his parents flipped a coin and the family moved to Los Angeles. While Flanagan never went to Catholic school and stopped believing in religion in the 1970s, events from his childhood involving Catholicism and sexual games played with his cousins ultimately shaped who he became as a sadomasochist and how he dealt with the chronic pain and suffering caused by cystic fibrosis.

Amelia Jones describes Flanagan as a poet who entered “the art world through performative sadomasochistic practices in private S/M clubs in San Francisco and Los Angeles.” From there, in the 1980s, Flanagan began performing his S/M practices in art galleries with his partner Sheree Rose. He would often read poetry while performing acts of sadomasochism. Two poems in particular, “Why?” (1997) and “Super Masochistic Bob with Cystic Fibrosis” (1997), exhibit Flanagan’s humor and sadomasochism as ways to cope with cystic fibrosis. Flanagan was always very engaged with his audience and very likable. His humor and charm made visitors almost relax while he self-deprecated or nailed his penis to a chair or board.

As Flanagan exposes his body one through his body two, a type of gestural exchange occurs between himself and his viewers. As a result, there is a demand for the spectator’s own self-conscious relation to the representation, and the acknowledgement of Flanagan’s own embodiment as a performative presence in the moment of witnessing not only his pain due to chronic illness, but his self-inflicted pain. In a sense, Flanagan’s self-inflicted pain in performance translates bodily experiences caused by chronic illness more effectively. He makes invisible pain visible in order to induce some type of emotion,

feeling, or bodily experience in the spectator, whether that emotion is compassion, empathy, anger, etc.

All of the descriptions of Flanagan's public and private performances show him as complete manifestation of Ihde's body one. The artist is completely in his body. During his private acts of sadomasochism, he is feeling, observing, and sensing every part of his body through a practice of complete self-control and self-awareness. And, during his public performances, he exposes himself as he is.

Johanna Hedva is a writer and performance artist who grew up in Los Angeles, California. On their mother's side, they are a fourth-generation Los Angeleno and, on their father's side, the grandchild of a woman who escaped from North Korea. Hedva is also a sound artist, an occasional installation artist, among other things. They live with a chronic condition that "about every 12 to 18 months, gets bad enough to render [them], for about five months each time, unable to walk, drive, do [their] job, sometimes speak or understand language, take a bath without assistance, and leave the bed." Where Flanagan is more concentrated on revealing the body as self, Hedva is undoubtedly focused on revealing the political as self and the self as political.

For Hedva, their performance *Sick Witch* is a "conduit to a state of emotion where the body is absent of the discrete self." This is what inspires me to think of Hedva and their performance as Ihde's idea of body two. While it can be argued that they are indeed revealing their body and self through their political identity while using their cane and

clothing as props, body one for Hedva is irrelevant here. In fact, they are obliterating the individual self in order to place emphasis on the lived condition itself. They take out the chronic illness of the self in body one and place it completely in body two.

Thus, by completely obliterating the self in order to place disability entirely into the political, public sphere, Hedva also places the sensory and bodily experience usually seen in private completely into the public. With pain caused by illness now placed in body two, Hedva's movements, verbalized pain, and gestures during their performance are easily exchanged between performer and viewer.

Bob Flanagan died of cystic fibrosis in 1997 after living 43 years with the illness. I also have cystic fibrosis, so I especially relate to Flanagan and his methods for revealing the invisible. In fact, I cannot even give this presentation without constantly coughing and drinking water. Over the years, cystic fibrosis has been described to me via doctors, nurses, therapists, respiratory therapists, social workers, etc., as a "life threatening disease. It is genetic, and it is chronic. In other words, you are born with it, and you live with it until you die.

My daily symptoms include: chest tightness, coughing, "abnormal" amount of infected, bloody mucus production in my lungs and sinuses, stomach cramping, diarrhea, acid reflux, nausea, headaches, fatigue, sinus pressure, scratchy throat, the list goes on. In order to eradicate these symptoms, my doctors have prescribed lists of breathing treatments and medications that, through my life time, have spanned into the hundreds.

After analyzing Flanagan's performances and Hedva's *Sick Witch*, I performed *Revealed Body*. Each person experiences something different when they perform in front of an audience. However, I wanted to perform for this project in order to understand the lived body experience and what it means to be embodied in front of an audience, in the public realm. I chose to look only at the camera filming in front of me instead of engaging with the audience because I distinctly wanted my body to be both subject and object of this work of art.

After the performance ended, I had a discussion with the audience about their experience during the performance. The silence, the constant coughing, and the sound of machines provided an atmosphere of extreme focus and meditation. Overall, everyone agreed that the largest impact was the realization of how long my treatment takes, and how many times a day I have to do it. As a result of this realization, the audience felt a sense of empathy and embodied a type of ethical spectatorship. It became clear that *Revealed Body* not only related to the other performances but became the body three of Hedva's body two and Flanagan's body one. This is so, because my performance is deliberately revealing my body one through my body two while using my breathing treatment equipment, thus making it body three. While it can be argued that each of the artists mentioned make the invisible visible by traversing both body one and body two into body three, each artist emphasizes one type of bodily experience in their performance.

Complex embodiments not only provide new perspectives in art making but also generate new methods for analyzing art and history. The way our personal/interior bodies feel

informs the way we reveal and see our identifiable bodies, and how we conform to our technologies, i.e. body one + body two = body three. As Amelia Jones explains “illness concretizes the body, forcing the subject to become hyperaware of her/theirs/its/his body-in-pain.” As a result of performing this hyperawareness, we are able to see one body respond to another as the performer is able to induce some type of emotion, mood, feeling, or bodily experience in the spectator.

Thank you.