Revealing Femmegimp: A Sex-positive Reflection on Sites of Shame as Sites of Resistance for People with Disabilities

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Abstract

This paper, which doubles as a call to action, draws on my personal experience, theoretical analysis, and sexually explicit self-portraiture to produce a sex positive reflection locating sites of shame as sites of resistance to western society's conceptualization of the body, regarding dependency, vulnerability, touch, and sexuality.

Résumé

Cet article qui sert d'appel à l'action tire de son expérience personnelle de l'analyse de la théorie et de l'auto - portait sexuel explicite pour produire une réflexion positive au sujet du sexe en repérant des partie du corps dites honteuses, comme des comme étant des parties du corps qui résistent à la conceptualisation du corps qu'a la société occidentale, en ce qui est relié à la dépendance, la vulnérabilité, le toucher et la sexualité. In the dominant culture there is little that affirms people with disabilities.¹ Daily, we confront ableist laws, policy, and attitudes, and media that alternately ignores our existence or depicts that existence as anything other than real. Representations render us as miserable, dependent, heroic, and entirely unattractive. This history of oppression continues to manifest itself through and in segregated schools, inaccessible housing and public transportation, "lives not worth living" rhetoric, the prevalence of pity, insufficient public support and attendant care, desexualization, isolation, condescension, abuse, neglect, stairs as well as stares, and shame.

People with disabilities and our allies have fought hard and long, and continue to struggle against these forces. Drawing on strength, creativity and hope, we are envisioning and building spaces where we can enjoy a quality of life of our own determination. We continue to create and find places where we are appreciated and celebrated for the very differences that are often used to justify our oppression.

My work reconceptualizes the body from a femmegimp perspective as an "out body" that openly defies assimilation. I draw upon the very points targeted as sites of shame, such as dependency, sex, vulnerability and being an "out" disruptive body, as sources for potential sexual and body liberation for all bodies. I also identify self-initiated sex-positive pornography that embraces these sites of shame as a means of reclaiming the gaze and staring down the systems of desexualization. I write this not just because it is important political and scholarly work that needs to be done, but also because it is personal.

I used to say that I could deal with the lack of curb-cuts, inaccessible buildings, difficulties finding a job, and so on, but it was in the lack of sexual affirmation and sexual love/affection in my life where I felt an incredible sense of loss. Many in the disability rights community have spoken to this hurt. As Anne Finger stated in Mitch Tepper's "The Missing Discourse of Pleasure," sex "is the source of our deepest oppression and our deepest pain" (Tepper 2000, 284). The emotional pain around sex and sexuality for people with disabilities is real and oppressive, in the most systemic sense. Numerous studies have provided ample evidence that while people who are disabled have the same range of sexual desires as able bodied persons, these needs are going largely unmet, having a negative impact on quality of life and sexual self-esteem (Mayers 2003; McCabe 2000).

More direct oppression occurs when persons living in an institution, such as a nursing home, are told it is against the rules to have sex at the home and will be asked to leave if they are discovered. A paternalistic approach to people with disabilities means that many are "protected" from pornographic images - that is, "protected" from viewing them. Many children who are born with or acquire their disabilities early on are told directly and indirectly to not expect anyone to ever love them. Only recently have people begun to express outrage about this site of oppression as honestly as we have for other issues of access. After all, the truth is that we want curbs-cuts and attendants, not just so we can go to work to pay our taxes, be good citizens and not be a burden on society, but so we can love and fuck and live fully.

Getting Stuck

Barbara Faye Waxman argues that the reason the disability rights movement has not placed sexual liberation at the forefront of the movement is that deep down we are afraid that we are "ultimately to blame for not getting laid; that it is somehow a personal inferiority. And in the majority culture this secret is a source of personal embarrassment rather than a source of communal rage against the sexual culture itself" (Waxman 1991, 89). Shame is clearly at work here. As Abby Wilkerson argues, drawing on the work of other theorists, "shame is not so much a psychological state of individuals as such (even though it may shape individual subjectivity), but rather a socially based harm which oppressed groups are subject to in particular ways...Shame is deployed as a 'political resourc[e] that some people use to silence

or isolate others'" (Wilkerson 2002, 45). The pain and loss of sexual oppression can easily be understood and explained as a personal or interpersonal problem or even as an attitudinal problem; however, as individual as shameful attitudes seem to be, they are clearly systemic in nature.

Empowerment, hope, passion, community, and pleasure are all necessary ingredients that move us toward social action. They are also crucial in healing from, challenging and defusing shame. Yet, loss and hope are not necessarily separately occurring phenomena. As Waxman argues, in the sites of our deepest shame lie the seeds of liberation and hope (Waxman, 1991). This is why there are such strong systems in place keeping us from critically knowing and drawing power from those sites of shame. This systemic use of shame allows for society to remain unchanged and unchallenged.

The cumulative effect of this extensive system of desexualization is felt in the lives of people with disabilities every day. It can mean numbing the pain and loneliness with alcohol and drugs (Roy 2003). It can mean "your only experience of touch is functional" and you may not know how good it can feel to be touched out of pure desire (Davies 2000, 188). It means it has been really hard for me to write this paper. Living under the above conditions can force people with disabilities to internalize the misguided notions that we are inferior, both sexually and in general, and this belief keeps us in a "state of sexual self hate" (Waxman 1991, 90). A state of shame.

Everyone wrestles with shame and the sexual culture itself is saturated with shame (Tisdale 1994). One of the main effects of shame is to keep us isolated and separate from our bodies/selves, and from each other. This isolation and separation from others and ourselves keeps us from unlearning the current body politic and discovering new ways of being in the world.

Being Out

We have all the "tools" we need to begin this resistance; everyone has a body and the potential to learn from that body and our experiences. This body of mine is not so special in some regards because the reality is that all bodies are disorderly, unstable, and not self-contained or sustaining

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(Shildrick 2002). With that said, however, the femmegimp body is one, among many others, that for a variety of reasons has been and is still considered abnormal, yes, even monstrous, by many in the normative community.

The experiences associated with my body and identity marked by queerness, femmeness and disability make it an appropriate site for this exploration and journey. While there are as many definitions of femme as there are femmes, the characteristic/quality many femmes agree upon is that femmes are disruptive (Duggan and McHugh 2002; Rednour 2000). A femme will catch your breath, dazzle your senses and muddy your binaries. Lisa Duggan and Kathleen McHugh write, "femme is neither an ideal nor a category...She makes a scene, an entrance, an appearance - she steals the show (she is the show of difference), but cannot be fixed as a certain effect in itself... she occupies normality abnormally" (Duggan and McHugh 2002, 156).

Such eloquent and adept definitions of gimps have not been as abundant in the literature as those for femmes, and more has been written and reclaimed in regards to Crip/ple. Crips and gimps are adamant in our refusal to be docile. We know that our presence makes the normative universal 'you' uncomfortable. Yet instead of acquiescing to a place of shame and servitude, gimps and crips are loud mouths that will deflect your discomfort back to its true source. Many of the articulations of new meanings for crip/gimp appear in discussions of the similarities between crip and queer. As Eli Clare argues, "queer and cripple are cousins: words to shock, words to infuse with pride and self-love, words to resist internalized hatred, words to help forge a politics" (Clare 1999, 70).

Queer and crip/gimp share a "defiant external edge" and "comfortable inner truth" (Clare 1999, 70). Through a defiant relationship with normality one can find inner comfort. Further, crip/gimp and queer intersect and intertwine with femmeness, becoming a femmegimp body and identity that resists the pressure to feel shame for its disorderliness. A body and identity that strives to bask in her asymmetrical curves dares you to as well. I do not wish to convey that there are any clear and definite boundaries associated with a femmegimp identity and body. A femmegimp identity relies on the inherent fluidity associated with the concept of becoming where one's identity and/or body is not fixed.

Being a Body

My phrase "being out about being a body" invokes the powerful and long history of resiliency by queers and gimps to fading away by minimizing their differences. This resistance occurs despite the many forceful structures urging us all toward conformity with a mainstream normative culture that is reliant on constructing and maintaining binaries. Susan Wendell writes in her chapter "The Flight from the Rejected Body," "those who appear 'abnormal' according to their society's standards are constant reminders to those who are currently measuring up that they might slip outside the standards. In this aspect, people with disabilities [and those who transgress normative gender] arouse fear" (Wendell 1996, 89). The fear arises when the hegemony of normative discourse is disrupted. The normatively privileged are so caught up in the act of trying to solidify that which is fluid that they don't see us (the "out" disorderly bodies of the world) or our potential beauty and wisdoms that everyone would benefit from. Wendell starts this conversation when she says, "If we knew more about pain, about physical limitation, about loss of abilities, about what it is like to be 'too far' from our cultural ideals of the body, perhaps we would have less fear of the negative body, less fear of our own weaknesses and 'imperfections,' of our inevitable deterioration and death" (Wendell 1996, 92).

Beyond the thought that disorderly bodies can simply offer a more positive way of dealing with things typically thought of as negative, such as pain, death, or deterioration, lie other lessons learned from "bodies that are out." Lessons united through the themes of touch, dependency, and vulnerability.

According to Elizabeth Grosz, in Cartesian thought, characterized by dualistic notions such as mind/body and "singular self" and "combined unit," the body is seen as functioning in three ways. These are the body as object (which dominates the biomedical approach), the body as a tool (either active which means the body requires discipline or training, or passive which means the body needs subduing or occupation) or body as a "signifying medium," a vehicle of expression, a mode of rendering public and communicable what is essentially private (ideas, thoughts, beliefs, feeling, affects) (Grosz 1994, 9). Clearly, these are limited depictions of bodies, all of which turn the body into something that can and should be fixed and controlled (clearly evidenced by the biomedical obsession with cures and restorative surgeries). These notions have serious implications for everyone, but most severely for those of us who are obviously disorderly.

A Phenomenology of Support

One of the experiences my femmegimp body has given me is that of someone who requires assistance to meet most of the basic needs of daily living. For my entire life I have had people around helping me prepare food, helping me get dressed, take a shower, change the batteries in my vibrator, get into bed and out again, use the toilet, and the list goes on. Therefore my body and all of its many functions and desires are presented to two or more people several times a day, every day. Because of this I, like many other out bodies, have very little privacy.

Related to the binary of public/private is the dualism of singular self/combined unit. One cannot have privacy when one functions as a unit, not just as a self. Most of the theorizing surrounding the combination of the self/other dualism into (a) body(ies) that function(s) as a singular self and combined unit centers on the maternal/infant and conjoined twin bonds. Here I would like to extend this thought to the bonds regarding personal assistance. Personal assistants are a vital part of my life, my existence, my environment, and my world. Merleau-Ponty says that the self and world are one. Therefore, in a sense, the people that help me and myself are one. This occurs, according to Merleau-Ponty, among other ways, through touch (Shildrick 2002). The care that I need requires a lot of physical and intimate touch and contact, not to mention coordination. References to dancing occur on many occasions as my personal assistants help me because of the constant conscious and unconscious negotiation that has to transpire between us. This negotiation occurs because my personal assistant and I, and our bodies, are functioning as a self and as a unit. Calling upon Merleau-Ponty's concept of reversibility as referenced in Shildrick, "it is never such that the two participants merge; there is always an excess. The chasm, the cross-over, is the point of both convergence and divergence; it is not a loss of distinction, but a coming together in difference" (2002, 111).

Many claims to normalcy necessitate a self-sufficient and wholly separate person. This is just not possible when you are someone who needs personal support. I would argue that it is this drive towards separation and turning away from dependency as a marker of adulthood, thereby insuring rights and validation, that ultimately fuels the devaluation of people who are outwardly dependant on others. As Shildrick continues, "the conventional model of subjectivity...has no room for corporeal being that is either uncontrollable or less than perfect. It is a model that disavows existential vulnerability" (105-6).

Shildrick argues, "in the move away from the phantasy of the wholly unified and self-complete embodied subject, we may lose the illusion of autonomy, but gain access to a more sustaining mode of becoming-with-others" (119). By focusing on the mutuality of these caring relationships, a deeper knowledge is shared. There are many wisdoms, not to mention laughs, that my circle of support and I have received from the interactions that occur from my being a femmegimp body that outwardly and daily needs care, and these contribute to new ways of being-in-the-world-with-others. This mutuality holds the potential for combating the shame that exists in non-normative relationships "with 'out bodies'" where one moves from fearing towards embracing the monster within. This can happen when one takes the disruptive qualities of both queer theory and disability theory and offers up the challenge to "take the shame on directly, proclaim our dependence, and challenge so-called able-bodied people on their unwillingness to be dependent" (Kelly 2002).

Coming and Becoming

Out bodies' necessary proximity and touch make remaining comfortably disconnected and distant from others and ourselves difficult. Shildrick states in Embodying the Monster that, "it is in the embodied gesture of touch that we may sustain a reciprocal sense of solitude and intimacy that is grounded in the mutual instabilities and unpredictability of our corporeal becoming. To touch and be touched speaks to our exposure to, and immersion in, the world of others, and to the capacity to be moved beyond reason, in the space of shared vulnerabilities" (2002, 117).

While the experience of the visibly dependant and vulnerable body that resides outside the established norm poses a "danger to the [current] body politic" (Wilkerson 2002, 45), you don't necessarily have to be part of a personal assistance relationship to experience and learn from the disruptive power of touch. Sex, because it is linked to the enjoyment of the body, is another area wherein lies the potential for disruption. During sex we are vulnerable and most of us are very aware of our bodies. Heartbeats, breath, exchanges of fluids and definitely touch all intertwine in the creation of (an) body(ies). Sarah Chinn describes the "out" "electricity" of sex as "the loss of self in concert with (indeed, dependent on) an intense sensory awareness of self" (Chinn 2003, 181). As with personal assistance relationships, there is fluidity between self and other and self and combined unit. In this space of disruptive fluidity, sex is about coming with others and becoming-with-others. Pleasure is partly why sex can be seen as disorderly and thus dangerous to normative ways of being. As Wilkerson argues, "sexuality is a vital means of pleasure, interpersonal connection, personal efficacy, and acceptance of one's body and of self more generally" (34).

Pleasure also propels us to face our fears and insecurities.

Sex positive people with disabilities are working hard to shift the discourse. They are not only challenging the silence surrounding the sex lives of the disabled, but shifting the way that people view disability, from undesirable to desirable. Ultimately the goal here is to move to a place where disabled people and our bodies are appreciated and wanted, not in spite of our differences, but because of them.

Furthermore we are working to remove some of the barriers to sexual participation. Tom Shakespeare (1996) and others call for the improvement of sex education information when it comes to disability. This would include providing accessible sexual health education, not as a segregated service for people with disabilities, but by incorporating disabled people's experiences into all sex education programs to counter assumptions that people with disabilities are inherently inadequate or incapable lovers (D'aoust 1999; Shakespeare 1996).

Many sex and disability activists have talked about ways to incorporate impairments into sex through word of mouth, guides, and shared details in essays and articles on what works for them, providing what has often been untouched by professionals (D'aoust 1999; Homosex 1999; Withers 2003). Throughout the self-published 'zines, Ring of Fire #3, If I Can't Dance is it Still my Revolution? and Sex on Wheels, the authors talk candidly about the constant struggle to feel sexy and be seen as sexual, avoiding the internalization of all of the cultural, political, structural messages that so totally devalue people with disabilities (Homosex 1999; Withers 2003; Alessia 2003). Members of the disability rights and culture communities, such as Hellery Homosex, call for pornography made for and by people with disabilities (Clare 2002; Homosex 1999; Withers 2003).

Becoming a Pornstar

Participating in this call for action, I want to examine the use of pornography made from a sex-positive feminist disability liberation perspective as a potential site of resistance. Pornography exists in many different forms and contexts, some of which may be used as a potential tool of empowerment and resistance to the desexualization of people with disabilities. This in no way attempts to ignore or justify the multitude of exploitative, harmful and oppressive conditions of pornography that exist (Elman 2001). Much of the attention to porn in the disability community has focused on the potential dangers associated with pornography, but very little research has been done on the potential benefits of self initiated involvement in porn.

I want to return briefly to my own story: I spend a lot of my life naked, to varying degrees, in front of people. I bare my skin, including my most private parts, on average, to at least three different people a day. If this sounds like the makings of a porn star to you, that's because it is - in a way. Certainly, it has encouraged or at least utilized the exhibitionist in me. From a very young age, I have been a very sexual person, who wanted to be desired. I didn't feel sexy though because the ways that I am sexy and sexual were not recognized.

The first time I remember even remotely feeling sexy was when I put on my first Victoria Secret bra when I was 22. How could this cute sheer black bra with a little bit of lace possibly look good on me if I wasn't sexy? When I looked down I couldn't believe that it was my breasts I was looking at because they were sexy. While I was discovering the joys of slutty clothes I was also immersed in feminist studies. Much of what I learned as a Women's Studies undergraduate served as a welcome relief from the dominant culture's image of women and enabled me for the first time not only to feel validated, but to be able to articulate and pinpoint the systems of oppression that generate devaluing and disempowering living conditions and the resulting shame. My darkest secret was the desire to be the object of desire. I wanted to be wanted for my mind and my body. I wanted people to look at me and get hot. I wanted to be a porn star.

I certainly didn't think this was possible. I was really different from the models and movie and porn stars who served as the markers of beauty. After lots of encouragement, my best friend who happens to be an excellent photographer convinced me to take topless pictures sporting my new nipple ring. One of these pictures was the first photo I ever liked of myself. It wasn't the same as the mainstream magazine/movie/porn sexy; it was something deliciously different. When I look at this picture and the others I have had taken since I feel sexy; I feel the beginning of liberation and revolution.

Much of the pornography that depicts people with disabilities has been driven underground because of the shame and stigma attached to displaying and delighting in disabled bodies (Doorne 2004). This is absolutely tied to the potential challenge posed to the status quo by the explicit depiction of the sexuality of people with disabilities. People with disabilities have held little control over how they are represented; therefore placing the power of representation in the hands of disabled people is a political act. Plummer articulates the reciprocal role of the storytellers and the larger community: "Stories and narrative depend on communities that will create and hear the stories: social worlds, interpretive communities, communities of money...these stories work their way into changing lives, communities and cultures" (Plummer 1997, 145). Sex-positive feminist pornography, as a form of sexual story telling with a broad and diverse community of creators and consumers, has the potential to educate, challenge, and transform the sexual climate and culture that surrounds disability (Hohmann 1997). Sex-positive feminism has illustrated many of the benefits that pornography made from this perspective has to offer women and these lessons can be applied to the experience of disability as well.

Sex-positive pornography from a feminist and disability liberation perspective would open up the circulation of information and new possibilities. The relationship between pornography and censorship is fundamentally an issue of access. As stated in The Sexual Politics of Disability, arguments regarding fetishism. oppression and exploitation become "entwined with issues of civil rights, access and the need to challenge stereotypical notions of normalcy and beauty" (Shakespeare 1996, 125). Any censorship of information most profoundly affects those who lack the power in society to determine which information is legitimate and important (Strossen 1995). As a result, even a pamphlet about safer sex that mentions sexual practices and how to protect one's self from sexually transmitted diseases is paternalistically kept from those who most need the information - or it is not created in an accessible format.

While it remains an area greatly contested in the disability community, many activists, scholars and individuals feel that this profound exclusion from the sexual culture only makes people more vulnerable to abuse, exploitation and oppression (Clare 1999; Shakespeare 1996).² In order for pornography to be safe and empowering, we don't need to restrict porn; instead we need to open it and allow more perspectives and people behind the camera and in control (Matrix 1996; Nagle 1997). Not having information about healthy relationships, or sexual expression, together with language mixed with shame, not only creates high-risk situations, but also limits the vehicles available to learn positive loving and sexual expression skills (Tepper 1997).

Being sexually expressive with impairments fosters creativity. Self-initiated pornography made by people with disabilities, featuring people with disabilities, would be an excellent format to highlight and share this creativity that many could benefit from. The distribution of pornography made by people with disabilities would also serve to diminish some of the mystery surrounding the sex lives of disabled people that fosters exploitation and fetishism. We are all doing pretty similar things in and out of the bedroom. In porn featuring people with no visible disabilities I have even seen what could be considered facilitated sex (two people were supporting someone's entire weight while they had sex with another person) something typically thought of as a phenomenon unique to the experience of sex with people with certain physical limitations (DeGenevieve 2002).

While pornography certainly should not be the only outlet available for sexual expression it can serve as a "sweet, but temporary escape from loneliness" (Matrix 1996, 96). Beyond simply providing information, and escape, pornography also stimulates an active fantasy life. There has been much written in the sex-positive feminist movement about the positive effects of masturbation in establishing one's sexual self (Strossen 1995). Acting sexy oftentimes leads us to feeling sexy (Nagle 1997; Rednour 2000) - and empowered. Although it is a contentious topic, there are many positive aspects to creating and posing for pornography in conditions of one's choosing. Self-proclaimed feminists, myself included, find themselves pleasantly shocked to find posing for "dirty" pictures beats away the nasty grip of shame on our bodies and our sexual expression (Matrix 1996; Nagle 1997; Rednour 2000). Not only is it a space to see your self as sexy and sexual, but the positive reactions of others provide relief and affirmation (Matrix 1996).

Self-initiated, sex-positive porn made from a feminist disability liberation perspective has the potential to give back control of the ways we are represented so we can finally see ourselves the way we want to be seen. What pro-porn disability activists hope to accomplish is to challenge the asexual stereotypes of people with disabilities and to refocus the glaring, gawking and gazing (Clare 1999, 2002, 2003; Homosex 1999; Withers 2003).

Now is the time to create images of people with disabilities that are sexy and sexualized, thereby challenging, displacing, and replacing the asexual images of the dominant culture. Images that show off some of the sites of shame make us face our greatest fears and insecurities face on. We need obviously disruptive bodies. We need those of us who do not necessarily have the ability or desire to deny our bodies or our needs and wants to realize that instead of only feeling the fear, shame, and loss that can permeate the ways we think and feel about bodies, there also resides comfort, beauty, and hope.

People with disabilities also need to be seen and recognized as the sexual and sexy beings we are because, as Samuel Lurie insists, "Pride and self-love, [are] mighty powerful byproducts of being admired and loved" (2002). Sex has the potential to expose us and our needs, wants, and vulnerabilities. As Lurie continues, "being desired, trusting that, reciprocating that, cracks us open" (2002). Part of this cracking open also cracks open society - which can be terrifying. Remaining open and vulnerable is scary because of shame, past hurts (systemic and interpersonal), and the very real chance of harm, but it is also important because the only other option is to be closed off from our selves as well as others. We need to trust each other and present our vulnerable selves to each other in order to truly become-with-others and live in a caring world. We need to draw upon the strength and the lessons of the obviously disruptive body, if we truly hope to come to understand all bodies.

In my own life, I often feel a push-pull struggle between hope and shame. One night, a partner and I were in bed. As we were kissing I had to ask them³ to move my head so I could kiss them better. I know there was no reason other than ingrained shame to feel bad about my request. In any other context I have no problem asking for help moving. However, in that instant I felt such loneliness and sadness. The person I was with simply placed their hand on the side of my face and turned my head. They left their hand on my cheek and we continued kissing. In this wonderful moment of connection, I placed my hand on theirs and felt the push of hope. I felt the potential that lies in recognizing sites of shame, such as vulnerability, dependency, sex, and being an "out" disruptive body, as sites of resistance.

Endnotes

I. My use of the terms "disability" and "people with disabilities" is meant to incorporate the interplay of lived experiences, sensations, and functions of the body with an understanding of disability as an experience that is produced contextually and culturally.

2. The minimal amount of discussion regarding the sexual abuse of people with disabilities in this paper in no way reflects a lack of importance in addressing these issues. It is, however, the aim of this paper to uncover the less direct, yet still detrimental, abuse that occurs as people with disabilities are desexualized.

3. The use of "their/them" is used intentionally here to respect this person's choice of preferred pronoun. Genderqueer people often use "they/them" or "ze/hir" in an effort to escape the gender binary confines of the pronouns "he/his" or "she/her."



Figure I









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Images

Photos taken in collaboration by Amanda Johns and Loree Erickson 2000-2003, Richmond, VA, and used with permission. Revealing femmegimp is a collection of photos that illustrate several of the concepts presented in this paper. I took these images in part to sexualize a femmegimp body, my body including my wheelchair, in a queer context. I took these photos to feel hot. I took these pictures to push myself as well as others. I took these pictures because I have someone in my life who is an amazing photographer, even when all she has around to use is a disposable camera. I know she sees me as sexy just by looking at these pictures. I also wanted to see myself, including those sites of shame and resistance (my asymmetrical curves, scars, and so on) presented center stage in conditions of my own choosing. In these pictures, I not only wanted to harness the power of the gaze and meet its eye but to stare the gaze down. I took these pictures because I want to be a porn star.

Figure I "As Is" Figure 2 "Connect" Figure 3 "Gaze"

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