

Care and Sexuality in Disabled/Nondisabled Intimate Relationships

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In a recent Mothers Against Drunk Driving commercial a young man is reading on a park bench and the screen reads “your best friend.” An attractive woman walks up and kisses him as the screen reads “your girlfriend.” The camera moves to the inside of an institutional-looking room with a man in a wheelchair gazing upon the pair and the text reads “you.” The screen fades to black and says “You have a lot to lose.” The intent of the commercial is to deter drunk driving, but the message hinges on understanding disabled people as sexless and isolated. Within this discourse, disabled people are not adequate friends or lovers because they need constant care to maintain their disabled bodies. They are “burdens,” not active participants in relationships, particularly in a sexual sense. Conversely, nondisabled spouses and partners of people with disabilities are assumed to be straddled with caregiver burden, strain, and ultimately, burn-out.

Representations reflect social attitudes, but they also set limits of possibility--they help define what is socially imaginable. The Mothers Against Drunk Driving commercial is both a symptom and agent of cultural beliefs about the meaning and nature of intimate relationships and care for people with disabilities. “Care” in relationships between disabled and nondisabled partners is constructed as a binary between care-givers and care-receivers. In other words, the disabled partner is represented as only a care-receiver and the nondisabled partner as only a care-giver. This dependency dynamic desexualizes nondisabled/disabled relationships because the care burden is expected to interfere with sexual intimacy. In the U.S., this image of care and sexuality between disabled/nondisabled partners is so strong it can be found in a variety of other

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fields and discourses that touch the lives of people with disabilities and their partners. For example, in the applied fields (e.g., rehabilitation, medicine, counseling) the assumption that nondisabled partners experience only burden is frequently built into research designs and it is rare for such studies to even measure sexual and marital satisfaction or positive aspects of caregiving. Similarly, contemporary feminist research constructs nondisabled partners as victims of a system that refuses to help caregivers, statistically female. It is true that family caregivers need help, but it is symptomatic of our beliefs about disability in intimate relationships that the disabled partners are erased in much feminist care research. Even in the disability rights movement, care is often downplayed because, in a culture that views care so negatively, it is only a liability to draw attention to personal care needs. In other words, disability rights advocates prefer to emphasize the similarities between disabled and nondisabled people. Thus, contemporary feminist research, the applied fields, popular culture and the disability rights movement—all relatively disparate discourses—engage in a surprisingly coherent, negative image of care in intimate relationships.

The voices of people involved in disabled/nondisabled intimate relationships are missing from this picture. My project turns to self-representations of people in disabled/nondisabled intimate relationships to illuminate alternative understandings of care and sexuality. I combine data from 1) focus groups I conducted as part of this project with 2) autobiographies and 3) documentaries made by people with disabilities and/or their partners for a triangulated research methodology that seeks multiple meanings of care and sexuality in nondisabled/disabled relationships. As self-representations, autobiographies and documentaries offer viewers a rich portrait of life with physical impairment, but they are also typically produced by people with certain levels of social and economic privilege. The focus groups, however, allow for greater

diversity. In addition, previous research suggests that couples that deal with disability report social isolation. Focus groups can, potentially, facilitate community building among couples experiencing similar forms of disability discrimination and isolation (Madriz 842). At each focus group¹, participants were asked to discuss how outsiders—friends, family, medical professionals, and strangers—treated their relationship, their opinions about disability and sexuality in popular culture, and how they defined and experienced care and intimacy in their relationship.

Contrary to dominant representations of care in disabled/nondisabled relationships, my research suggests that the boundary between caregiver and care-receiver is often blurred. That is, the disabled partner gives care and the nondisabled partner received care and vice versa. In addition, physical care is often part of sexual intimacy.

Reciprocity

Self-representations by people involved in disabled/nondisabled relationships emphasize mutuality and reciprocity, and offer expanded notions of intimacy, sexuality, and care. For example, “interdependency” is a prominent feature of many self-representations.

Interdependency emphasizes the way in which we are all dependent on each other. The disabled partner is not only the receiver of care, but also a provider. The nondisabled partner may give care, but he or she also receives care and recognition. Disability autobiographies make obvious such reciprocity and connectiveness, exploring how subjectivity, or identity, exists only in relation to another.

¹ Participants in the focus groups were composed of couples in which one partner was able-bodied and the other partner had a physical impairment and needed assistance with at least one activity of daily living (e.g., bathing, dressing). In addition, to be eligible, the couple had to have lived together with the impairment for at least one year and both partners had to be free of emotional or cognitive disabilities. I conducted four focus groups with 2-4 couples in each (total of 24 participants or 12 couples). The focus groups were conducted in Akron, Cleveland, Columbus, and Dayton during the summer and fall of 2007. All names have been changed to protect the confidentiality of participants.

For example, Bonnie Sherr Klein's autobiography Slow Dance: A Story of Stroke, Love, and Disability is interdependent in content and form. Klein refuses sole authorship in a variety of ways. First, she uses a coauthor, feminist writer and performer Persimmon Blackbridge, to construct the text. Secondly, she includes the writings of friends, doctors, and family members next to hers. Most prominent are the writings of her husband, Michael, and children, Naomi and Seth. Together, these voices narrate Klein's experience with becoming disabled through stroke because, as she notes, "we are living this together" (329). For Klein, telling her story with a singular voice would pervert the way in which her experience of disability has been interdependent. Her disability identity has been formed through the reactions, emotions, and thoughts of those important to her, thus, their voices are central to her story.

Nancy Mairs' Waist-High in the World: A Life Among the Nondisabled suggests that the activities of caregiving help make interdependence obvious. Describing her life with MS as "a project, in which others must participate if it is to prosper," Mairs explicitly connects her body to the bodies (and experiences) of others (especially her husband, George) (71). The chapter called "Taking Care," beautifully highlights the interdependency Mairs' body has with other bodies. The argument throughout the chapter is that it is just as psychologically and physically important for Mairs to be able to provide some form of caregiving to the people she loves, as it is for them to care for her. Although she has had to change the way she takes care of others, she insists that she is more than a body cared-for. Primarily her care-giving takes the form of intellectual and emotional efforts. In addition, she writes that "permitting myself to be taken care of is, in fact, one of the ways I can take care of others" (83). Here, Mairs expresses the reciprocity so central to Nel Noddings' conceptualization of "care relationships." Noddings' formulation of caring emphasizes the role of both parties—the ethic of being cared-for as well as the one-caring.

Noddings insists that relations, not individuals, define the caring relation (xiii). “By recognizing the carer’s efforts, by responding in some positive way, the cared-for makes a distinctive contribution to the relation and establishes it as caring” (ibid.). Thus, caring is a reciprocal relationship which hinges on recognition of the other’s subjectivity.

The subjectivity of both partners is emphasized in self-representations by drawing attention to the ways in which the disabled partner also gives care. Shameless: The ART of Disability (Bonnie Sherr Klein 2006) follows five disabled activist/artists in Canada--Bonnie Sherr Klein, Geoffrey McMurchy, David Roche, Catherine Frazee, and Persimmon Blackbridge. All but one of the main characters is in a relationship with a nondisabled partner, thus, relationships are a major theme in the film. Klein is careful to show how her disabled friends care for their partners—Frazee is a successful lawyer and provides economically and intellectually for her partner, Roche adds humor to his relationship, and Persimmon and her partner create art together. Shameless also includes an interesting sequence with Klein and her husband Michael in which they openly discuss why Michael stays with Klein after the stroke. In voice-over Michael says,

The men of women who’ve had strokes leave their wives a shocking 80% of the time.

Why didn’t I leave? Oh, poverty of imagination, I suppose. [Laughter] No, I didn’t leave because our relationship basically didn’t change. I mean that’s the major issue, that Bonnie takes care of me. And she took care of me when she was in the ICU and quadriplegic, she was taking care of Seth and me and Naomi.

While Michael says this we see him help Klein across a rocky beach and into a canoe that they then paddle together. This sequence highlights the ways in which Klein continues to take emotional care of her family, despite the physical care she now requires.

In the focus groups, couples explained that they are careful to figure out ways in which the disabled partner can give care to the relationship. For example, Emma has cerebral palsy and needs help with dressing, eating, bathing and toileting. Despite this level of physical care, she and her partner Richard insist that their relationship is characterized by mutuality and reciprocity.

Emma: -- I guess you can't look at physical care as something that's unequal in the relationship because I care for him by taking care of the bills and making a budget and remembering our calendar and, um, you know—

Richard: --ya, we try to maximize everything, maximize her participation in everything just by letting her—when she can do something its hers!

Emma and Richard are aware of the need for Emma to participate and give back in the relationship. Because Emma's impairment limits what she can do physically, her form of care takes the shape of brain-work. Thus, part of the work of the disabled/nondisabled couple involves assessing what the disabled partner can do and assuring that he/she becomes responsible for those activities. As Dan, who has a spinal cord injury, explains, "I do those things because those are the things that I can do." Dan can't mow the lawn or do house maintenance, but he can vacuum the floors and do the laundry. Ways in which the disabled partner can reciprocate and give care to their nondisabled partner are actively sought and acknowledged in order to maintain a sense of equality.

Non-Heteronormative Sexuality

The physical care required in disabled/nondisabled relationships places couples in unique body-aware situations. On her relationship with George, Nancy Mairs writes:

We carry on a constant, often hardly conscious, corporeal conversation regardless of our other pursuits and preoccupations. Without my disability to throw us together thus

habitually, our bodies might spend their days racing separately from one activity to another, coming across each other only in time to tumble into sleep. (54)

Here, it is specifically her severely disabled body that makes possible an interdependence that also enhances the intimacy of her relationship with George, a possibility that may in fact be lost to “normates” caught in the web of mainstream demands and values of bodily separation, individuality, and self-reliance.

Couples in the focus groups felt that physical caregiving activities often enhanced intimacy. For example, when asked how providing care interacts with sexuality or intimacy in the relationship, Richard and Emma respond:

Richard: It enhances it, I think. [laughter]

Emma: [inaudible] When you're in the shower and he is bathing me its—its not sexual but yet it is, you know, I can't explain it the right way—

Richard: --It's a...um, high level sexual, but I mean, it is certainly not, certainly not intercourse but its its pleasurable, its pleasurable.

Emma: It is very intimate...it is a very loving, sensual, state-of-being

For Richard and Emma, the routine task of bathing has become part of their sexual intimacy.

Another participant, Allison, who is blind, explains that holding hands with her partner Jason is a way for them to express intimacy and closeness even though, on a practical level, he is simply guiding her across a street. In both these examples, the disabled/nondisabled couple is able to eroticize care activities to enhance intimacy.

Similarly, Gene, the nondisabled partner of Victoria who has muscular dystrophy, explains:

I'm trying to think of the best way to put this. There are times when it kind of increases intimacy, and I'm talking both sexual intimacy and just the closeness. In fact, I think we get a lot more closeness out of those up close and personal moments that we have together...Looking at other relationships before her, I would say this is the closest, strongest relationship, and I'm sure that that [physical care] has a lot to do with it.

Here, Gene is arguing that the physical care not only enhances sexual and emotional intimacy, but makes them stronger and closer than nondisabled couples. This sentiment is echoed by other participants as well. For example, Sabrina, who has multiple sclerosis says, "I think truly it makes you closer than it does other couples because you have to deal with things that you'd never have to deal with." In Sabrina's case, her partner Adam has had to catheterize her when she is unable to do it herself, thus, she feels that their relationship exhibits more trust and intimacy than nondisabled couples.

Documentary films made by people in disabled/nondisabled relationships re-work and expand normative ideas about intimacy and sexuality. For example, in Loree Erickson's erotic video called Want (2007), typical scenes of lesbian sex (albeit with a wheelchair involved) are juxtaposed with scenes of Loree receiving help with toileting. We see Loree giving fellatio to her partner's dildo in the bathroom and her partner digitally penetrating her next to scenes of Loree being cared-for by friends and lovers—transferred on an off the toilet, getting help with dressing, etc. The effect of this sequencing is to associate care with sexuality and intimacy. Want is about desire, intimacy and sexuality; thus, by including these caregiving moments, Loree is explicitly expanding the concept of caregiving to include intimacy and sexual expression.

In a very different tenor, Sick: The Life and Death of Bob Flanagan Supermasochist (Kirby Dick 1997)² shows how Bob Flannagan and his partner Sheree combined treatments for cystic fibrosis with sexual expression through sadomasochism. For Flanagan, regular floggings were sexually satisfying, but they also had the therapeutic effect of clearing Flanagan’s lungs of mucus, thus explicitly blending “care” and sexuality (McRuer 182).

Care and sex/intimacy are also blended in Shameless, albeit less explicitly. After Frazee returns from the hospital we see her and her partner at their cottage in the woods, enjoying nature and time together. The audience even becomes privy to a romantic bubble bath the two take. Significantly, however, we do not just see the two in the bath—we are also shown how her partner gets Frazee into the tub using a mechanical lift. In this case physical care is necessary during sexual intimacy, but Frazee and her partner continue to exude love and happiness. This sequence helps make clear that the care Frazee needs in no way obstructs sex/intimacy.

Thus, in all three forms of self-representation—autobiography, documentary, and focus groups—couples acknowledge that the disabled body requires physical, personal care. Instead of hindering sexual intimacy, couples felt that this care helps intimacy. In fact, these self-representations seem to suggest a blurring of care and sexuality, in which care contributes to the couples’ overall intimacy. Of course, bathing, dressing, toileting, and transferring are not normative forms of sexuality or intimacy. Because of this, I believe that disabled/nondisabled sexuality—even when heterosexual—is truly “queer” in the “queer theory” sense of the word. As this research makes clear, non-heteronormative ways of expressing love and sexual desire are common in disabled/nondisabled intimate relationships.

Conclusion

² Although Kirby Dick is credited as the director, Bob and Sheree participated in all creative decisions; therefore, I classify Sick as a self-representation.

Self-representations contradict the binary and asexual relationship between disabled and nondisabled partners popularized in academic research and mainstream media.

Disabled/nondisabled couples emphasize reciprocity, mutuality, and eroticized daily care in their relationships. These findings help correct popular stereotypes and suggest that reciprocal relationships and alternative forms of sexuality should be considered in future research on care and disability. Thus, on a practical level, understanding the ways in which disabled/nondisabled relationships are characterized by reciprocity, and the ways that couples are intimate and sexual, may improve the treatment of people in disabled/nondisabled relationships. Instead of assuming burden and asexuality, professionals, friends and family may be able to see love and mutuality.

These findings are also significant on a theoretical level. As Robert McRuer argues in his recent, groundbreaking book Crip Theory: Cultural Signs of Queerness and Disability, queer theory and disability studies have much to learn from each other. Both are dedicated to the intellectual project of “working the weakness in the norm” by exposing compulsory heterosexuality and compulsory able-bodiedness, respectively (Butler 26, qtd. in McRuer 30). McRuer puts forth “crip theory” as a way to understand how the “severely disabled/critically queer body...remaps the public sphere and reimagines and reshapes the limited forms of embodiment and desire proffered by the systems that would contain us” (31).

Disabled/nondisabled couples expose how limited dominant understandings of care really are—how care has become synonymous with burden, and how care can be otherwise. By expanding care to include sexual intimacy, and by focusing on the ways in which disabled partners reciprocate in the care relationship, disabled/nondisabled couples “crip” or “queer” the meaning and nature of care, disability, and intimacy.

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