Sexuality and Disability, Vol. 18, No. 4, 2000

Sexuality and Disability: The Missing Discourse of Pleasure

Mitchell S. Tepper, Ph.D., M.P.H.[1,2]

In the realm of sexuality and disability there is public discourse on deviance and inappropriate behavior, abuse and victimization, asexuality, gender and orientation with regard to women, and reproductive issues in women and men. However, there seems to be a missing discourse of pleasure. The purpose of this talk is to shed some cultural and historical insight into why this may be so, to argue why sexual pleasure is important to quality of life, to point out a few of the consequences of not including a discourse of pleasure, to share some of my research on sexual pleasure in people with spinal cord injury (SCI), and to make a plea for inclusion of sexual pleasure in the disability studies agenda.

KEY WORDS: sexuality; disability; pleasure; disability studies.

I truly stand on the shoulders of giants. Before I get started I would like to acknowledge a few people. First, Michelle Fine has influenced my thinking with regard to the missing discourse of pleasure. Once upon a time, many years ago, I read an article she wrote called "Sexuality, Schooling, and Adolescent Females: The Missing Discourse of Desire" (1). In it she argued that the anti-sex rhetoric surrounding sex education and school-based health clinics does little to enhance the development of sexual responsibility and subjectivity in adolescents and in fact serves to increase experiences of victimization, teen pregnancy, and school dropout. She also argued that inclusion of desire in the sexual discourse serves to empower young females to be sexual agents, entitled to pleasure and therefore responsible for their own sexuality. Fine details a discourse of desire as follows:

[1]President, The Sexual Health Network.
[2]Address correspondence to Mitchell S. Tepper, Ph.D., M.P.H., 3 Mayflower Lane, Shelton, CT 06484; e-mail: mitch@sexualhealth.com.

0146-1044/00/1200-0283$18.00/0

> A genuine discourse of desire would invite adolescents to explore what feels good and bad, desirable and undesirable, grounded in experiences, needs, and limits. Such a discourse would release females from a position of receptivity, enable an analysis of the dialectics of victimization and pleasure, and would pose female adolescents as subjects of sexuality, initiators as well as negotiators (p. 33)

I have simply extended her thinking to the context of sexuality and disability in the words to follow.

Next, not second, there is Barbara Faye Waxman. Nearly 10 years ago, in the pages of the disability rag, she led the battle cry with an article entitled, "It's Time to Publicize Our Sexual Oppression" (2). She asked, "Why hasn't our movement politicized our sexual oppression as we do transportation and attendant services?" And was so bold to state her belief that it is "because 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" (p. 85). Then there is the voice of Ann Finger who once noted sexuality as a source of our deepest oppression and our deepest pain. And lastly, and I know I leave out many like Susan Knight (3), who were also pioneers in the field of sexuality and disability from our own disability perspective, I'd like to take take my hat off to Tom Shakespeare, Kath Gillespie-Sells and Dominic Davies for their groundbreaking book, *The Sexual Politics of Disability: Untold Desires* (4).

So what I'm here to say is not entirely new or original. Yet I hope my perspective can add additional insights and serve to keep the momentum going. My foundation is not in disability studies per se but in business, in public health, and in human sexuality. I have been a member of the disability community for almost 18 years and have been formally doing research on sexuality and disability for the past 10 years. I have developed a curriculum to teach health professionals how to provide comprehensive sexual health in rehabilitation programs (5) and taught that program to hundreds of medical students and experienced rehab professionals. I also conduct sexuality education workshops for young people with disabilities ages 14–21 and for adults with disabilities. For the past four years I have been addressing the questions of hundreds of people with disability or illness via my website sexualhealth.com, with the help of some volunteers in this room, namely Drs. Russell Shuttleworth and Linda Mona.

SEXUAL PLEASURE IN A CULTURAL PERSPECTIVE

The pleasurable aspect of sex in our culture has been largely ignored, vilified, or exploited. Our families, public schools, religious institutions, and medical establishment have adopted the "don't ask, don't tell" policy of sexual education. In fact, the United States government has funded, to the tune of $500

million, an abstinence-only-until-marriage act that does not allow for classroom discussion of sex as a vehicle for expression outside of heterosexual marriage. The dominant cultural institutions have effectively silenced public discourse of sex as a source of pleasure in our lives.

One institution that has not ignored sexual pleasure is the media. However, the media has exploited sexual pleasure for gain. Sex is portrayed as a privilege of the white, heterosexual, young, single and non-disabled. Sexual pleasure is held out as a reward for buying the right product and targeted to markets with the most disposable income. Sexuality as a source of pleasure and as an expression of love is not readily recognized for populations that have been traditionally marginalized in society. Sexual portrayals of people who are older, who are larger, who are darker, who are gayer, who are mentally or physically disabled, or who just do not fit the targeted market profile have been conspicuously absent in mainstream media.

The discussion of pleasure in populations such as women, older Americans, large sized people, gay, lesbian, bisexual, and transgendered individuals, and children is also underrepresented in the medical or scientific research literature. This is equally true for people with disabilities. A biologically determinate viewpoint of sex as solely the province of reproduction, and reproduction solely the province of the fittest, usually those with access to the full enjoyment of citizenship, has largely served to exclude people with disabilities. In addition, a social cultural viewpoint of sex as a source of danger leads to the presumed need to protect us. Disabled populations are not viewed as acceptable candidates for reproduction or even capable of sex for pleasure. We are viewed as child-like and in need of protection.

Alex Comfort in *Sexual Consequences of Disability* (6) summed up the situation as follows:

> Besides the pressures of folklore, individuals whose mobility is limited or whose deformity is evident are exposed to other forms of attack upon their sense of worth and desirability. Cultural constructs, such as a wholly unrealistic emphasis on physical beauty or strength as an index of being desirable, and the practical barriers of finding a partner, all combine to make the aim of sexual self-validation seem better given up; the relief of hospital staff and relatives with this renunciation becomes evident and may contribute to it, even though they do nothing to remedy the frustration and loss of self-value which may accompany it. (p. 3)

Societal attitudes toward people with disabilities have largely served to quiet both personal and political discourse on sexual pleasure and disabilities until most recently.

SEXUAL PLEASURE: A HISTORICAL PERSPECTIVE

We have a tendency to explain American avoidance of frank discussions of sexuality on our American Puritan Ethic. While it is true we can trace much of

our sexual phobias to the Puritans, the root of the problem goes back over 2000 years. A review of the history of pleasure in western philosophy, religion, and science lends insight to the development of modern day sexual mores held by cultural institutions including family, school, religion, medicine, and law. Sexual pleasure has been conceptualized as a lesser good, a sin, a sickness, and a perversion.

Western thinking and attitudes about sexual pleasure can be traced back to Greek dualistic thought juxtaposing soul and body. Pleasures of the flesh were ranked as the lowest of goods based on the superiority of the soul and reason. Plato relegated sexual desire to the lowest element of the psyche because "copulation lowered a man to the frenzied passions characteristic of beasts" (7, p. 14). The Catholic Church adopted many of the Greek's philosophical tenants about bodily pleasures and, over time, strengthened the negative attitudes and beliefs about sexual pleasure, promoting sexual pleasure to the status of sin (7). It is not until the period of the Renaissance and reformation (circa 1500 CE) when Puritans reared their heads. The Puritans and later the Victorians in the late 1700s to mid 1800s endowed us with the first system of laws against "obscene" or objectionable words including any direct reference to sexual matters.

In the late 18th century and early 19th century with the increased popularity and reliance on doctors and the medical profession, sexual pleasure was thought of or viewed as disease or sickness instead of sin, making it now a medical problem. According to Bullough and Bullough (7), the adoption of the medical model of sexuality substituted the view that all nonprocreative sexual activity was a sign of sickness for the earlier conception of sexuality as sin. Physicians "conceived their purpose to be a moral one" (p. 220), emphasizing the dangers of premarital, extramarital, or unusual sexual activities, not the pleasures of sex, and thus impaired the understanding of the physiological and psychological importance of sex in human beings (7). From this point on, the medical profession including psychiatry has played a central role in defining what is normal sexual behavior and what is deviant.

With the turn of the century came Freud and the advent of psychoanalytic theory when deviations from the heterosexual procreative model of sex were softened to the status of immaturity. Oral sex, anal sex, clitoral orgasms, inversion (what we know as homosexuality), lingering at foreplay were all perversions (8). Feelings of loathing, shame, fear and pain, as well as moral and aesthetic demands, were supposed to keep us on the path toward the definite and "excepted normal limits" or sexual aim of heterosexual intercourse.

It was not until the mid 20th-century with the groundbreaking research of Alfred Kinsey (9,10) and Masters and Johnson (11) that sex and sexual pleasure began to be demystified and normalized as a natural part of life in the United States and worthy of scientific attention. With the increased attention on sexual

pleasure came a heavy focus on sexual performance and orgasm as the goal of healthy sexual expression. Deviations from "normal" sexual response culminating in orgasm as described by Masters and Johnson (11) were viewed as human sexual inadequacies (12) and began to attract much interest. Human sexual inadequacies in nondisabled populations became the focus of sex therapy. While serving to liberate us from restrictive notions of sexuality, the new sex research with the help of distortions from the media that exploit people's sexual insecurities, has created an orgasm imperative in our culture (13). If someone who is not disabled does not desire sex, they have hypoactive or inhibited sexual desire disorder. If a nondisabled person does not have an orgasm, they have orgasmic disorder and qualify for treatment.

However, if a person with a disability has low sexual desire or does not experience orgasm, this is not seen as problematic. Neglect of the pleasurable aspect in the discourse of sexuality and disability is perpetuated by the assumption that people with disabilities are child-like and asexual (14), a focus on procreative sex to the detriment of pleasure (15), and the assumption that people with disabilities are not physiologically capable of pleasure or orgasm. To this day, in DSM IV (16), both female and male orgasmic disorder must be distinguished from a "Sexual Dysfunction Due to a General Medical Condition" (p. 515) when the dysfunction is judged to be due exclusively to the physiological effects of a specified general medical condition. "Spinal cord lesion" (p. 506) is used as the example of such a condition in women. This is evidence that normal science (17) still operates under a paradigm that views orgasmic disorder in people with at least some disabilities as a given.

Fortunately, social political movements by other sexually disenfranchised groups are gaining power and have brought into public discourse the discussion of sexuality and pleasure among their constituencies, opening doors to research and writing that address sexual pleasure. Women have found a voice for themselves through the feminist literature and women like Drs. Beverly Whipple and Gina Ogden educating other women (18) and telling their stories (19). Gay, lesbian, bisexual, and transgendered activists continue to make strides in challenging the straight community and have won representation and inclusion in popular movies and prime-time sitcoms through pressure on Hollywood. Older Americans have found their sexual voice spurred on by Bob Dole and Pfizer's promotion of Viagra, along with recent research on sex and maturity sponsored by AARP (20). "Fat" people are speaking out as evidenced in a new book by Hanne Blank called *Big Big Love* (21). However, with the exception of works of a few brave heroines in the disability movement, some noted earlier, and until the publication of *Sexual Politics of Disability: Untold Desires* (4), sexual pleasure in people with disabilities has remained remarkably silent in the disability advocacy and the disabilities studies agenda. People with disabilities are just joining the fray.

WHY DO I THINK SEXUAL PLEASURE IS SO IMPORTANT?

Pleasure is an affirmation of life. Pleasure is often defined as an addition to life or a form of luxury rather than a centrally motivating and defining feature of social action (22). Virginia Johnson (23), speaking to the significance of sexual pleasure, refers to pleasure as "the authentic, abiding satisfaction that makes us feel like complete human beings" (p. 28). Pleasure adds meaning to our lives. Sexual pleasure is particularly powerful in making one feel alive. It is an anecdote to pain, both physical and emotional. In fact, the analgesic effect of sexual pleasure has actually been measured in laboratory studies (15,24). Sexual pleasure can enhance an intimate relationship. It can add a sense of connectnedness to the world or to each other. It can heal a sense of emotional isolation so many of us feel even though we are socially integrated. It can help build our immunity against media messages that can make us feel as if we don't deserve pleasure.

CONSEQUENCES OF IGNORING PLEASURE

When we do not include a discourse of pleasure we perpetuate our asexual and victimization status. We do nothing to alleviate what I see as endemic low sexual self-esteem among the many people with disabilities and illness who participate in my research or who come to me for help. Negative sexual messages about people with disabilities fuel negative attitudes and misguided beliefs about sexual potential and take their toll on sexual self-esteem. Low sexual self-esteem combined with the likes of physical limitations, diminished sensation, lack of escalating arousal, difficulty with ejaculation, or difficulty with orgasm may make sex and sexual relationships seem pointless, may reaffirm unexpressed beliefs of asexuality, and may lead to the conclusion "why bother."

In my dissertation research I explored knowledge, attitudes, beliefs, and cognitive processes that impede or facilitate sexual pleasure in people with SCT. After injury things were "not the same." There were concerns about being sexual in the "normal" way. Feelings of "not the same" were rooted in who, what, where, and how participants learned about sexuality in the larger sexual culture. These changes experienced in comparison to memories of what was normal for them before injury resulted in intrusive and uncontrollable thoughts during sexual activity. The absence of quality sexuality education combined with learning about sex primarily from having genital intercourse, led to sexuality embodied in the genitals and cognitively focused on perfect performance with the goal of orgasm. This genitally focused and performance oriented conception of sexuality presented developmental challenges to optimizing sexual potential after injury for all participants. Learning about sex from having sex

and from media that exploits the pleasurable aspects of sex and not learning about other aspects of sex from family, schools, clergy, or doctors resulted in consequences like low sexual self-esteem and lost hope that surfaced when genital sensations and function were "not the same" or impaired along with other bodily functions subsequent to SCI. Participants who relearned how to experience pleasure and even orgasm after SCI believed early on that there was more possible and that their sexuality was their responsibility. They learned more about their spinal cord injured bodies, introduced fantasy; embraced the disability and rejected sexist and ablest ideals, and were fortunate enough to experience sex with a significant sexual partner. The deliberate inclusion of pleasure in this research brought to light the most compelling issues around sexuality and disability for the participants.

THE REAL ACCESSIBILITY ISSUE

In the words of Benjamin Seaman, a visitor to sexualhealth.com, access to pleasure is "the real accessibility issue." What are we doing it all for? Full inclusion means access to pleasure. It means a reasonable chance for relationships. The blame cannot all be placed on society. We as a group must push forward this agenda, educate ourselves, and share what we know to be real truths about sexuality with the non-disabled community that is equally crippled by distortions of sexuality in the media. We must be advocates for the inclusion of sexual pleasure in disability studies, politics, and public discourse.

ACKNOWLEDGMENTS

This study was funded by the National Institutes of Health Predoctoral Fellowship Award for Students with Disabilities.

This paper is based on my doctoral dissertation research conducted at the University of Pennsylvania Graduate School of Education Program in Human Sexuality Education, Philadelphia, PA.

REFERENCES

1. Fine M: Sexuality, schooling, and adolescent females: the missing discourse of desire. Harvard Educational Review 58(1): 29–53, 1988.
2. Waxman BF: It's Time to Politicize Our Sexual Repression, The Ragged Edge: The Disability Experience from the Pages of the first Fifteen Years of The Disability Rag. Edited by Shaw B. Louisville, The Advocado Press, 1991, pp. 82–87.
3. Bullard DG, Knight SE: Sexuality and Physical Disability: Personal Perspectives. St. Louis, C. V. Mosby Company, 1981, pp. 318.

4. Shakespeare T, Gillespie-Sells K, Davies D: The Sexual Politics of Disability: Untold Desires. London, Cassell, 1996.
5. Tepper MS: Providing comprehensive sexual health care in spinal cord injury rehabilitation: Continuing education and training for health care professionals. Huntington, CT, Mitchell Tepper, 1997.
6. Comfort A: Sexual Consequences of Disability. Philadelphia George F. Stickley Company, 1978.
7. Bullough VL, Bullough B: Sin, Sickness, and Sanity. New York, New American Library, 1977.
8. Freud S: Three Contributions to the Theory of Sex. New York, Nervous and Mental Disease Publishing, 1930.
9. Kinsey AC, Pomeroy WB, Martin CE: Sexual Behavior in the Human Male. Philadelphia, W. B. Saunders Co., 1948.
10. Kinsey AC, Pomeroy WB, Martin CE, Gebhard PH: Sexual Behavior in the Human Female. Philadelphia, W. B. Saunders Company, 1953.
11. Masters WH, Johnson EJ: Human Sexual Response. Boston, Little, Brown and Company, 1966.
12. Masters WH, Johnson V: Human Sexual Inadequacy. Boston, Little, Brown, 1970.
13. Gardetto DC: Engendered sensations social construction of the clitoris and female orgasm, 1650–1975, Graduate Division. Davis, University of California, 1992, pp. 350.
14. Fine M, Asch A: Women with Disabilities: Essays in Psychology, Culture, and Politics. Philadelphia, Temple University Press, 1988, pp. 347.
15. Whipple B, Richards E, Tepper M, Komisaruk BR: Sexual response in women with complete spinal cord injury, Woman with Physical Disabilities. Edited by Krotoski DM, Nosek MA, Turk MA. Baltimore, Paul Brookes, 1996, pp. 69–80.
16. Diagnostic and Statistical Manual of Mental Disorders. Washington D.C., American Psychiatric Association, 1994.
17. Kuhn TS: The Structure of Scientific Revolutions. Chicago, The University of Chicago Press, 1970.
18. Whipple B, Ogden G: Safe Encounters: How Women Can Say Yes to Pleasure and No to Unsafe Sex. New York, Pocket Books, 1989.
19. Ogden G: Women Who Love Sex. New York, Pocket Books, 1994.
20. Jacoby S: Great Sex: What's Age Got to do with It? Special Report on the AARP/Modern Maturity survey on sexual attitudes and behaviors, Modern Maturity, 1999, p. 41–45, 91.
21. Blank H: Big Big Love: a sourcebook on sex for people of size and those who love them. San Francisco, Greenery Press, 2000.
22. Tiger L: The Pursuit of Pleasure. Boston, Little, Brown and Company, 1992.
23. Masters WH, Johnson VH: The Pleasure Bond: A New Look at Sexuality and Commitment. Boston, Little, Brown and Company, 1974.
24. Whipple B, Komisaruk BR: Elevation of pain threshold by vaginal stimulation in women. Pain 21(4): 357–67, 1985.