

Sexuality and People with Psychiatric Disabilities

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This article explores the topic of sexuality and intimacy of people with severe mental illness by addressing a series of questions about the nature of psychiatric disability and its effects on sexual identity and behavior. After describing the characteristics of people with psychiatric disabilities, the paper explores where they fit in the disability rights movement and examines how society treats persons with psychiatric labels. Barriers to full sexual expression are explored, first, from consumer perspectives, and then from the research literature, including a look at impediments to use of contraception and safer sex practices. Finally, the analysis asks a series of questions about issues for women mental health consumers in the expression of their sexuality and access to women's health services, along with sexuality issues for gay, lesbian, bisexual, transgender, and HIV-positive consumers. Finally, the paper concludes with suggestions for ways the disability community and larger society can support mental health consumers' efforts to freely express their sexuality and combat stigmatizing societal representations of it.

KEY WORDS: sexuality; intimacy; mental illness; psychiatric disability.

INTRODUCTION

Increasingly, the sexuality of people with disabilities has become the focus of serious local and national research and advocacy activities. The present article addresses this topic by identifying the nature of psychiatric disability and the position of mental health service consumers in the disability rights movement. Next, the analysis explores societal and professional treatment of people

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with psychiatric labels, especially regarding their sexuality. Following this is a discussion of research findings from a survey conducted by mental health consumers, exploring intimacy in the lives of a sample of people with serious mental illnesses in California. Research on barriers to sexual expression among mental health consumers is then reviewed, along with what is known about their difficulties in using contraception and safer sex. Issues for women mental health consumers in the expression of their sexuality and access to women's health services are described, along with sexuality issues for gay, lesbian, bisexual, and transgender consumers, as well as individuals who are HIV-positive. Finally, the analysis concludes with suggestions for ways in which multiple communities can support mental health consumers' efforts to freely express their sexuality and combat stigmatizing societal representations of it.

WHO ARE PEOPLE WITH PSYCHIATRIC DISABILITIES?

Not everyone with mental health problems experiences disability as a result. Individuals with psychiatric disabilities are those who have been *labeled* with a severe mental disorder referred to as an Axis I diagnosis included in the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) (1). Typical diagnoses include severe depression, bipolar disorder (popularly known as manic depression), schizophrenia, personality disorder, post-traumatic stress disorder, and obsessive compulsive disorder, among others. However, a diagnosis alone is not enough to define this group of individuals. They also are people impaired by severe psychiatric symptoms such as psychosis (being out of touch with reality), obsessions (ideas that one cannot stop thinking about), compulsions (behaviors one can't stop performing), overwhelming and unpleasant emotions (feeling sad or anxious most of the time on most days), and cognitive processing difficulties (hearing voices or an inability to concentrate or think clearly). Individuals are considered to be *disabled* when their levels of impairment interfere with their functioning in adult roles, creating difficulties living independently, maintaining employment, completing or advancing their educations, and relating interpersonally to others. Some argue that an individual's psychiatric disorder itself is far less important than the disabling environment in which he or she must function (2). In this view, disability does not stem from the individual's deficits or impairments but from the interaction between these and non-supportive, even hostile, environments (3).

At the same time, however, people with psychiatric disabilities manifest considerable *strengths*. These include being more *accepting of difference* among other people and more tolerant of diverse and alternative viewpoints. Many consumers are very *self-aware* given that they receive so much feedback about their emotions and behavior from clinical and social service professionals.

Those who have had years of experience with this disability often develop a set of *survivor skills* that stem from being forced to exist on very low levels of income, dealing with a capricious social service system, and coping with highly inadequate resources. They often are people with a *sensitivity to oppression* and a strong desire not to oppress others, given their experiences with curtailment of their own civil rights in the name of treatment. Finally, some consumers have a tendency to challenge “accepted reality,” asking why things are as they are, and having the ability to envision alternatives, some of which are ideas that make others uncomfortable or uneasy by upsetting the status quo.

WHERE ARE MENTAL HEALTH CONSUMERS IN THE DISABILITY RIGHTS MOVEMENT?

People with psychiatric disabilities are relative latecomers to disability rights activism (4,5). To some extent, this is because, for most of this century, large number of consumers spent significant proportions of their lives residing in state institutions. Only in recent decades, since their deinstitutionalization from public hospitals beginning in the 1950s and 1960s (6,7), have they been living in the community for long periods, providing the capacity for social and political participation (8). They’ve experienced minimal self-determination since society has not provided them with adequate mental health services or choices in how to use them when available (9,10). Moreover, as will be argued later, there is still great societal ambivalence about whether people with psychiatric disabilities are capable of knowing what is best for themselves and making informed choices. They were, however, active participants in lobbying for the passage of the Americans with Disabilities Act (11), and in recent disability-related legislation such as the Ticket to Work and Work Incentives Improvement Act (12).

Mental health consumers also are engaged in building increased acceptance for peer support and self-help among policy makers and mental health/rehabilitation professionals. While peer counseling is a central feature of the independent living movement and was even a mandated service in the Rehabilitation, Comprehensive Services and Developmental Disabilities Act of 1978 (13), peer support and self-help did not become a major policy issue for the mental health community until the 1980s and 1990s (14). The notion of consumer-controlled self-help (i.e., without professional supervision or involvement) has been ignored or rejected by many clinicians who feel that consumers are too unstable to assist each other without oversight from non-consumers (9).

The past decade has seen construction of representations of “recovery” versus cure, where recovery refers to a process by which one re-envision one’s life following the onset of a psychiatric diagnosis (15). The emphasis here is

not so much on “curing” symptoms and impairments but, instead, on controlling them as much as possible in order to fashion an existence with dignity, maximal self-determination, and the highest level of role functioning possible. It is the thesis of this analysis that *expressing sexuality and establishing intimacy is part of the recovery process for consumers*.

Perhaps because of the supposed “mental” rather than “medical” nature of their disorders, this disability group lacks an independent living movement such as that established among the physical disability community (3). Perceptions persist that consumers are not as deserving as other groups of housing assistance and support (16). Consumers are organizing politically and focusing on presenting a united front while allowing for diversity and acceptance of multiple viewpoints in their movement. Given that they value their unique perspective on reality, they are unwilling to “homogenize” in order to gain power (2). They seek room in their movement for dissenters and for those with high levels of symptoms and impairments.

HOW DOES SOCIETY VIEW AND TREAT PEOPLE WITH MENTAL ILLNESS?

It is important to understand the larger context in which changes are occurring. People with disabling mental disorders, particularly during the acute and florid phases of their illnesses, are deprived of their civil rights in the name of treatment and public safety in institutional settings (17–19). Mental illness is one of the few disabilities where people run the risk of losing their freedom in order to receive inpatient treatment; one is considered to be legally committed (either voluntarily or involuntarily) to a psychiatric inpatient setting. Increasingly, this is occurring in community settings as well, evidenced by the recent passage of Kendra’s Law in New York State (20) and a lessening of the severity of commitment criteria nationwide (21).

A strong force of social control of individuals with mental illness is the stigma and fear they experience, partly because of cultural representations of their “dangerousness” in the media. Their medical treatment often includes coercion involving emotional intimidation, threats, and bullying, as well as occasional forced restraint, forced seclusion, and chemical restraint. Many argue (22) that such “treatment” victimizes or re-victimizes individuals, perpetuating illness rather than enhancing health and well-being, and preventing many consumers from ever seeking formal treatment again.

Outside the clinical realm, individuals with disabling psychiatric disorders are objects of culturally-acceptable humor, scorn, and humiliation. It is still socially acceptable, even in today’s atmosphere of supposed political correctness in American society, to mock people with psychiatric problems, make fun

of psychiatric symptoms, and use stigmatizing language. Examples of all of these abound in the media, including joking about, imitating, and making light of symptoms and behaviors that are painful and humiliating for those who experience them (23). Some have argued that institutionalized discrimination against people with mental illness is one of the last socially-acceptable, government-sanctioned threats to the rights of a large class of vulnerable individuals. Finally, people with severe mental illness are not perceived as “legitimately” disabled by large segments of society, but instead as malingerers or whiners whose expression of their discontent and insistence on protection of their civil rights is viewed as evidence of insanity itself. To a large extent, this may be due to the well-documented episodic nature of many severe disorders, making it difficult for uninformed citizens to believe that individuals can decompensate and recover rapidly, enhancing perceptions that individuals are “faking” their problems.

WHAT ABOUT SEXUALITY AMONG PEOPLE WITH PSYCHIATRIC DISABILITIES?

While U.S. society prefers to view people with mental illness as asexual (24), studies show that many are sexually active, with from one-third to three-quarters reporting engaging in sexual relations depending upon the time frame asked about (25–27). In addition, research shows that most people with mental illness do not practice safer sex (28) or understand pregnancy or STD prevention (29,30). A series of studies in the 1990s showed that large proportions (66% to 75%) did not use condoms during sexual activity. In a survey of over 750 mental health consumers at a community-based rehabilitation program in Chicago (24), 72% said they did not regularly use condoms or dental dams during sex. Many consumers have difficulty using contraception for reasons that are economic, interpersonal, and situational (31). While consumers report enjoying their sexuality, they also report less physical and emotional satisfaction than their non-disabled counterparts in some studies (32,33). Many say they repress their sexuality, worry about its “normalcy,” and internalize societal disapproval of their sexuality. To some extent, sex involves “letting go” and this can be difficult to those who fear loss of emotional and behavioral control.

WHAT DO MENTAL HEALTH CONSUMERS SAY ABOUT THEIR OWN SEXUALITY AND INTIMACY?

In 1990, a survey of 325 mental health consumers was conducted by peer researchers in the California Department of Mental Health led by Dr. Jean

Campbell and associates (34). Just over half (51%) of the consumers surveyed said they lacked a satisfying sex life; just under half (47%) said they lacked a satisfying social life. Two-fifths (40%) said they lacked warmth and intimacy. Interestingly, there was a connection between consumers' housing situations and opportunities for intimacy. Over 50% of board-and-care residents reported lacking privacy in their everyday lives, which impeded their ability to establish intimate relationships. However, there was some evidence that lack of privacy was only part of the problem, since 50% of respondents felt that people with serious mental health problems were incapable of having satisfying intimate relationships.

WHAT BARRIERS EXIST TO SEXUAL EXPRESSION AMONG MENTAL HEALTH CONSUMERS?

Even though people with psychiatric disabilities are sexually active and view sex and intimacy as essential for their well-being and self-determination, a series of barriers prevents them from expressing their sexuality. As mentioned earlier, lack of privacy in many residential settings, including mandatory room sharing and "no sex between residents" policies, create few opportunities for healthy sexual self-expression (35,36). Histories of childhood and adult abuse and trauma constitute another barrier, one encountered disproportionately among both men and women consumers (37). For example, a growing literature shows that anywhere from 36% to 85% of women mental health consumers in the public system have experienced traumatic abuse including physical and sexual abuse as children or adults (38,39).

Partly due to their disorders and partly to societal stigma, people with psychiatric disabilities lack self-confidence and experience very low self-esteem that can impair their ability to establish intimacy with others (40). Sex involves a degree of risk-taking and vulnerability that can be difficult for everyone and especially so for those with low self-confidence. Psychiatric medication side-effects also can diminish sexual performance and desire, causing erectile dysfunction in men and inorgasmia in women (41). Certain symptoms (paranoia, withdrawal) inhibit peoples' ability to form relationships and maintain them. But beyond symptoms themselves, peoples' ways of relating interpersonally can be impaired; for example, avoidance of eye contact and inability to manage casual conversation are two typical social skill impairments, related to some forms of psychiatric disability, that are essential to establishing intimacy. As a result, some consumers may appear less desirable to potential partners. Finally, people with mental illness receive very little assistance and support from service providers for expressing their sexuality, especially practical assistance with social skills and support for sexual activity (42,43).

WHAT DIFFICULTIES DO CONSUMERS REPORT USING CONTRACEPTION AND HAVING SAFER SEX?

Successful contraception and safer sex practices can be difficult for all kinds of sexually active individuals. One of the most serious barriers to use of contraception and safer sex among people with psychiatric disability is lack of knowledge and information. Since case managers and clinicians often feel uncomfortable discussing sexuality with their clients (28,44), consumers receive very little education in this area (45). Families may feel ambivalent about or disapprove of their relative's sexual activity (46) resulting in a lack of support from relatives for using contraception and safer sex. In addition, the most effective methods of contraception such as birth control pills or IUDs are not affordable for those on limited incomes (31). Lack of privacy in residential settings may lead to hurried, unprepared-for sexual activity that is not protected. Finally, the social skills needed for negotiating safer sex (such as persuasion or limit-setting) are challenging for everyone, but especially for people with emotional difficulties, who may be seeking to have sex with other individuals facing the same sorts of emotional problems.

WHAT SPECIAL ISSUES ARE FACED BY WOMEN MENTAL HEALTH CONSUMERS?

Women consumers encounter special needs and issues regarding intimacy and sexuality. As mentioned earlier, rates of childhood and adult physical, sexual, and emotional abuse are especially high for women consumers. As a result, many have trauma-related needs that remain unaddressed in adulthood and can interfere with the ability to establish relationships or engage in fulfilling sexual activity. Domestic violence also is a concern, in one rare study (47) of the topic, 26% of female psychiatric inpatients reported being abused by a spouse or partner at some time, with 19% reporting partner abuse within the past year. Studies of domestic violence against homeless adults indicate that women are more likely to be victims of domestic violence than men (48) and that domestic violence often contributes to a woman's homelessness due to her need to terminate the relationship (49). Another hindrance is the fear of unwanted pregnancy for women who have sex with men and experience difficulty using contraception. Child rearing responsibilities facing many single mothers may inhibit privacy and consequent opportunities for sexual intimacy even when desirable partners are available. Lesbian, bisexual, and transgender consumers encounter limited understanding and support from clinicians and society in general, as discussed later. A documented lack of women's healthcare (such as regular gynecological and breast examinations) for women consumers creates problems

for women with untreated (50). Some medications may inhibit sexual desire or arousal, interfering with sexual functioning (inorgasmia in women and erectile dysfunction in men). Finally, societal repression of women's sexuality in general (51) affects women mental health consumers who internalize negative attitudes about themselves as sexual beings with sexual needs.

WHAT SPECIAL ISSUES ARE FACED BY GAY, LESBIAN, BISEXUAL, AND TRANSGENDER CONSUMERS?

Using epidemiological data regarding the incidence of severe mental illness as well as homosexual self-identification in the general population, Hellman (46) estimates that anywhere from 200,000 to half a million gay men and lesbian women have severe psychiatric disorders. Studies show that a large majority of the general population's gay, lesbian, bisexual, and transgender communities have been the target of verbal abuse (92%) and nearly a quarter (24%) report having been physically attacked (52). Heterosexism and homophobia persist in the therapeutic community as well, resulting from gaps in the education and clinical training of therapists (53,46). Aware of overwhelmingly negative societal attitudes toward their sexual orientation, many patients hide their sexual orientation from health care providers (54). This creates a need for affirmative treatment models in both inpatient and outpatient settings, including psychoeducational approaches, support groups, and day treatment as described by Ball (55), Hellman (46), Helfand (45), and others. Without such services, sexual minority consumers face unnecessary barriers to establishment of intimacy and sexual expression.

WHAT SPECIAL ISSUES ARE FACED BY HIV-POSITIVE MENTAL HEALTH CONSUMERS?

Another vulnerable population with specific sexuality needs are those mental health consumers who are HIV-positive. HIV infection rates are notably high among this population (24), ranging as high as 40% in homeless groups (56). Lack of coordination between the mental health and HIV/AIDS care systems makes integrated services difficult to obtain (57). Disclosure regarding multiple statuses (as a person with HIV/AIDS, mental health consumer) adds to the burdens faced by these individuals. Special prevention services are needed by sexually active HIV+ consumers. These include the need for peer support groups and peer counseling (24), the need to address any co-occurring substance abuse issues (58), and the need for support for adherence to complex regimens of highly active antiretroviral therapies for HIV (59). A final point

worth mentioning is lack of training of clinicians and resulting discomfort or outright homophobia in mental health service provider communities and stigma about mental illness among providers in the HIV field (44). Consumers living with HIV may thus face a “double whammy” of discrimination in accessing needed services and supports.

WHAT CAN THE COMMUNITY DO?

There are many ways in which the community at large can support those with psychiatric disabilities. The disability community must stand solidly in support of this group’s right to sexual self-determination and expression of sexual identity. There also is a need for stigma reduction about mental illness in all professional fields and advocacy organizations, including the disability rights movement. Consumers need empowering environments and care providers, and this need must be met in the areas of cognitive as well as physical disability by the provider community. Affordable contraception and safer sex materials should be made available through the medical community. The consumer community can move forward by incorporating sexual expression and intimacy goals into its movement agenda. Finally, the larger community can educate itself about how to stop stigma against mental illness.

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