Missing Links

Women. Mental Illness and the Need for a

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L'auteure explore les deux arguments présents dans les programmes actuels de prévention du sida et suggère de développer à l'avenir, des programmes de prévention du VIH et de promotion de la santé sexuelle qui reflèteront une pratique féministe qui sera en même temps génératrice de pouvoir chez les femmes atteintes de maladie mentale.

Although women constitute over half the general population and almost two-thirds of the psychiatric patient population, many studies of mental illness1 do not report women's data separately and many do not include women (Penfold and Walker; Brunette and Drake). Similarly, information about or pertinent to women at risk of HIV infection has been concealed within study data or neglected all together. Although the lack of information about the sexual and drug-using behaviours of people with serious mental illness at first impeded the development of appropriate AIDS prevention efforts, it is now widely assumed that people living with mental illness may engage in "sexual risk behaviour" because of "their inability to evaluate appropriately their HIV risk" (McKinnon 25). In spite of this knowledge, and the knowledge that women are more biologically at risk for HIV infection than men,2 the HIV prevention needs of women have gone largely unconsidered. There is a great need to develop comprehensive and appropriate HIV prevention and sexual health promotion strategies and programs with and for women living with mental illness.

If the HIV prevention needs of women living with mental illness are addressed at all, the emphasis of most Women living with mental illness also experience higher rates of sexual and physical victimization and STD infection than men, which increases their risk of sexual ill health.

service planners is on strict HIV infection prevention education, with very little attention paid to the larger aspects of healthy sexuality. Within such programs, specific ways in which issues such as gender, class, ethnicity, and "mentalism" intersect to influence the lives of women are ignored and the social problems that affect women's lives are often blamed on the individual. Thus, HIV/STD prevention programs frequently begin with the assumption that it is appropriate to deal with social issues as individual problems for which there should be an individual solution (Penfold and Walker). Even so, these programs appear to be very rare. In fact, no descriptions of HIV/ STD prevention programs specifically developed for women could be found in the literature surveyed for this work.3 It appears that HIV prevention and sexual health promotion programs for women living with mental illness-programs that focus on the larger issue of overall sexual health as

it relates to physical, mental and spiritual well-being in addition to HIV/STD transmission—are largely non-existent. Such health promotion programs would have the opportunity to work with participating women to explore the larger issues of sexual health and to promote the personal empowerment of women living with mental illness (Kalinowski and Penney).

While briefly critiquing two existing HIV/STD prevention programs developed for men and women living with mental illness, I will explore two common assumptions prevalent within current HIV prevention programs and make suggestions as to how HIV prevention and sexual health promotion programs for women living with mental illness might be developed in the future to reflect an empowering, feminist practice of public health planning.

A Brief Review of Current Programming

Although studies of mental illness rarely report women's data, a few studies have reported a number of facts regarding the sexual health of women living with mental illness (Brunette and Drake). In spite of their experience of cognitive or relational difficulties, women with mental illness have active social and sexual lives. Although their sexual lives are often affected by prescribed treatments for mental illness (for example, neuroleptic medications have been known to increase libido in women and to increase their sexseeking behaviour), women are also known to have better-developed social circles than men who live with

New Model of HIV Prevention and Sexual Health Promotion

similar illnesses (McKinnon). Women living with mental illness also experience higher rates of sexual and physical victimization and STD infection than men, which increases their risk of sexual ill health (Brunette and Drake; McKinnon). These social and physical factors, combined with diagnosed (but not necessarily accurately assessed) factors of cognitive impairment, poor judgment, impulsivity, passivity, disadvantaged social and economic status, increased substance abuse, and interaction with others with high risk behaviours combine to place women living with mental illness in a position where they are not able to control their exposure to further, harmful infections (Friedrich and Grannon). Institutional factors play into women's experience of ill health as well. Due to recurrent hospitalization, longterm relationships are disrupted which can reinforce the tendency to have unfamiliar sexual partners (McKinnon). Institutional obstacles to condom acquisition also impede people's initiative to practice safer sex (McKinnon). Finally, a lack of self-esteem, a lack of confidence to plan ahead, and damaged interpersonal skills can all contribute to behaviour linked to poor sexual wellbeing, defined in its broadest sense (McKinnon).

In spite of these alarming reports on the status of women's sexual health and physical risk of HIV infection, there are few programs that seek to address the multi-faceted material, social, and emotional needs of women living with mental illnesses. If they focus specifically on groups of women at all, HIV and STD prevention programs seldom consider the fact that

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women face problems, such as unemployment, poverty, and disempowerment, which hinder their ability to follow through with prescribed safer sex techniques (Penfold and Walker). Most programs are based on a combination of medical and behavioural models that focus on "a disease model for emotional distress" which creates additional problems for women whose distress is often due to other social circumstances that the disease model then attributes to "deficits in their biological makeup" (Kalinowski and Penney 128). Such programs use prescriptive behavioural models in an attempt to assist people "in gaining the behavioural skills needed to effectively handle situations they are likely to confront" (Otto-Stalaj, Stevenson, and Kelly 117). Many programs teach safe sex behaviours, communication/ negotiation skills, and problem-solving skills to avoid or develop alternative strategies to handle risk "triggers." Yet, most of them have either been inconclusive as to their actual benefit to the participants or have not been evaluated (Otto-Salaj et al.).

One particular reported project located through the literature search detailed a ten-session behavioural intervention program for psychiatric outpatients focusing on safer sex education, condom use and negotiation. This project was found to be fairly helpful with 85 per cent of participants responding correctly to nine out of ten of the final knowledge questions and 89 per cent saying that they were more likely to use condoms during sex following the intervention. Seventy-five percent indicated that they were less likely to have sex with people they did not know and overall condom usage at the institution increased by 400 per cent. Although this project seems to have a positive short-term impact on participant sexual behaviour, its longterm results have not been evaluated and its results cannot be generalized because the authors did not detail the relevant life factors of the program participants (such as the gender, socio-economic, and education status) that would allow a reader to make a decision as to the program's usefulness in other educational situations (Herman et al.). Nevertheless, this HIV/STD prevention program does describe moderately successful approach to information dissemination in spite of the fact that it illustrates only one step in the direction of a comprehensive program for overall sexual health.

A similar project carried out by S.C. Kalichman, K.J. Sikkema, J.A. Kelly, and M. Bulto focused on four, 90-minute sessions with 52 psychi-



Rochelle Rubinstein, "Nurse #7," woodblock print, draped, photograph & heat transferred, 11" x 17", 2000

atric outpatients addressing topics such as: HIV risk education, identification of personal triggers that lead to sexual risk-producing situations, demonstration of condom use and practice of condom application using phallic models, discussion and generation of personal strategies for implementing risk reduction behaviour change, and interpersonal communication and negotiation skills. After the intervention, the program group had significantly higher scores in condom-use knowledge and AIDSrelated knowledge, stronger initial intentions to use condoms and an increase in the number of conversations with sexual partners in the past month regarding safer sex than the waiting list group (Kalichman et al.). Like the first project project detailed above, this project illustrates several

valuable educational strategies for the prevention of HIV and for sexual health promotion. Yet, these programs fail to demonstrate a consideration of the internal (self-esteem, self-confidence) and external (material resources, political influence) experiences that will affect the long-term impact on HIV infection prevention and sexual health maintenance.

Along with the neglect of complex internal and external factors in the lives of women who live with mental illness, existing HIV and STD prevention and sexual health promotion programs such as those discussed above make two related, yet subtle, assumptions that are not immediately evident to the program planner.

The Assumption of Individuality

When addressing issues of HIV and STD infection prevention, program planners and health educators often assume that women who live with mental illness, and who take prescribed "appropriate" medication, are willing and able to behave as autonomous individuals in the determination of their own sexual practices and overall health. As "risk managers" responsible for their own overall health, in addition to being responsible for the health of their partners and children, women are often assumed to be individuals who not only have the ability to determine their own health practices, but to also influence the health practices of their families. As such, program planners assume that HIV/STD prevention education and sexual negotiation coaching are the keys to women's sexual health and overall safety from infection. They presume that the transfer of information will be sufficient to give women the tools to take control of their sexual lives and to exert their right to choose between safe and unsafe sexual behaviour.

The Assumption of Agency

Similarly, program planners and health educators assume that women have the ability to demonstrate agency in their daily lives as they determine their own individual sexual actions and health decisions. Like the assumption of individuality, the assumption of women's agency is poorly founded because it is difficult to know whether vulnerable women living with mental illness truly make decisions that they feel are best or whether they choose certain, sexual options ("safe" or "unsafe"4) because they feel they have no other choice. It is entirely possible that vulnerable women will feel that they are pressured to comply with harmful sexual activity because they think they have no other financial, emotional, or spiritual options. For this reason, Baylis, Downie and Sherwin opt to reject the traditional individualistic view of autonomy upon which current concepts of agency are based. They claim that with the pressures facing vulnerable people and the power gap between them and potential sexual partners, it is false to claim that they are able to make an "autonomous" decision based purely on individual self-interest. They favour a more nuanced "relational" approach that considers the role that oppression plays in the choices made by vulnerable program participants. They claim that the oppression of vulnerable people is so deeply entrenched in our culture that it often goes unnoticed (by the vulnerable people themselves and by program planners trying to help them). The oftendesperate financial and emotional

situation of marginalized women means that many program participants may be overly compliant with a sex partner's requests (Baylis et al.). Sherwin's concept of "relational autonomy," challenges the traditional concept of autonomy, commonly understood to represent "freedom of action for agents who are paradigmatically regarded as independent, self-interested, and self-sufficient" (34), upon which conventional notions of sexual decisionmaking agency are based. Sherwin contends that since no one is fully independent of others and oppressive situations, the traditional notion of autonomy

fails to account for the complexity of the relations that exist between persons.... It idealizes decisions that are free from outside influence without acknowledging that all persons are, to a significant degree, socially constructed, that their identities, values, concepts, and perceptions are ... products of their social environment. (35)

Furthermore, the traditional concept of autonomy ignores the broader social and political contexts in which choices are made by those who are vulnerable to abuse or exploitation: "[it] ignores the oppressive circumstances in which individuals are invited to exercise choice" (Baylis et al 256). Sherwin's concept of relational autonomy makes visible the importance of considering how social factors affect vulnerable people's decision making, and it invites us to "consider how the burden of unjust social demands might be made explicit so that it can be separated out of the calculations [when considering the quality of a program participant's ability to freely make a sexual health decision]" (41). Program planners must promote vulnerable people's relational autonomy in all phases of the program process while understanding and anticipating the social forces that may influence a participant's decision to engage in sexual activity (Baylis *et al.*).

Developing a Comprehensive, Feminist Sexual Health Promotion Program

The World Health Organization (WHO) defines health as a "state of complete physical, mental and social well-being." As has been demonstrated thus far, current HIV and STD prevention programs do not address the multifaceted elements of overall health as defined by the WHO. Nevertheless, efforts must continue to develop comprehensive and holistic sexual health programs for women. Rather than an emphasis on simple HIV/ STD transmission

prevention and health education, such programs should focus on the promotion of the physical, emotional, mental, and spiritual aspects of women's sexual health through empowerment and education. Such a health promotion program would need to be facilitated by a diverse team of program subject-participants (the women living with mental illness) and professional program participants (the people whose job it is to work with and for women living with mental illness). The program would also need to have to have many facets that address multiple aspects of women's overall sexual health.

The first element of a comprehensive sexual health promotion program would have to be the professional team's firm commitment to



Rochelle Rubinstein, untitled, from the Genesis series, woodblock print, draped, photograph & heat transferred, 11" x 17", 2001

the women participants' self-definition of overall health and sexual health. Women program participants must be given the authority to define health in a way that makes sense to them and that definition must be honoured throughout the program if the program is ever going to make an impact on participants' long-term health. It is essential that the professional team be willing to work with women participants to identify and deal with individual and collective perceptions of the roots of oppression and ill health. The professional team must concentrate on respecting women's assessment of themselves and commit to working with them to mitigate and adapt to internal and external circumstances in a manner acceptable to the women participants. It is also essential that women participants be given the authority to co-develop the health promotion program. People who have experienced the mental health system often have profoundly different views on mental health than do professionals and their meaningful participation in program decision making must be allowed to have a significant impact on the way problems are conceptualized and solutions identified. Given that self-determination is perceived by people living with mental illness to be a "prerequisite for recovery," it is imperative that the goal of any health promotion program has this as an explicit goal (Kalinowski and Penney 131).

Such a commitment to women's self-determination will be very challenging to both professional staffparticipants and women-participants. Indeed, the professional will have to be introduced to new ways of dealing with clients and will have to be taught to refrain from measuring the reality of the person's experience against their own worldview (Kalinowski and Penney). The professional team will have to make a concentrated effort to provide a comfortable and safe space in which the women may disclose and discuss personal issues (Brady). They must also seek to engage potential participants in defining their own goals for the program and then collaboratively design and implement services that directly reflect these stated goals. One model of this collective self-definition and action process is called concept mapping. Concept mapping provides an opportunity for program participants to work together as a group to develop an understanding of a concept, and places the participants in control of interpretation (Campbell and Salem). As a group of women are assembled to discuss an issue or concept, they collectively move toward a group understanding of that concept, which is then represented in a visual picture, or map. A subgroup of participant advocates are then brought together to interpret the concept map and clusters of broad-based and specific system changes are identified by participants (Campbell and Salem).

Such methods of empowering women are very challenging for program developers and staff program participants. When confronted with a situation in which a client does not

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take up improved opportunities or does not take control of her life, it is easy to try to revert to old models of staff domination and control of program development and facilitation. Yet, as highlighted by Kalinowski and Penney, such apparent program "failures" may lie in the staff's conception of empowerment itself. Empowerment is not necessarily an "innate aspect of human existence" and not all people are "equally capable of making choices and directing their lives" (Kalinowski and Penney 132-133). Once someone is given authority to decide, it is not a given that they will assume control and responsibility for her life and the professional team should not expect that this will happen. Indeed, "choices are largely determined by external factors such as resources, legal authority and finances" (Kalinowski and Penney 133).

Kalinowski and Penney suggest the possibility that empowerment is more of a developmental process, with both external and internal determinants. Such a model assumes that people experience an ongoing process of growth and skill development "that improves their abilities and understanding regarding choices and the direction of their lives" (133). The external determinants that affect women's lives will affect the woman's overall "scope of choices and availability of resources" (Kalinowski and Penney 133). Program planning teams must be willing to work to engage in community development and to expand informational, housing, legal, political, and material resources for program recipients that will "enhance the breadth and weight of the individual's choices" and allow them more opportunity for self-determination (Kalinowski and Penney 141).

The internal mandate, on the other hand, focuses on the "development of faith, hope, personal value, and meaning" within a woman who is participating in the program (Kalinowski and Penney 133). This mandate highlights the need for staff and women participants to work together one-on-one and as a group, to expand a woman's "knowledge of choices [and her] ability to develop options and an awareness of the extent to which one's behaviour is or can be chosen" (Kalinowski and Penney 143). Part of the internal mandate is to guide participants in their understanding of the forces of oppression in their lives-to, as a group, become "more aware of the impact of misogyny and mentalism on [the lives of women]," and to understand that an individual's identification of and reaction to oppression is an essential part of the person's recovery and healthy outlook (Kalinowski and Penney 143). The work of the internal mandate is also to uncover unconsciously held harmful self-beliefs, through group work and consciousness-raising that can and do influence behaviour in a negative way. Such negative self-beliefs influence mental functions of perception, inference and memory and

eventually influence the behaviour that produces the ultimate confirmation of the original belief (Banaji). These "self-fulfilling prophecies" should be gently confronted and worked on, individually and collectively, by the women participants and professional team in order for women participants to fully realize their own self-worth and potential for health (Banaji). It is essential for program developers address issues of both the external and the internal mandate. Just as it is essential to address external barriers to empowerment, it is also necessary to support the person's internal mandate with one-on-one or collective feedback, encouragement, and evaluative discussion (Kalinowski and Penney).

Part of addressing the external and internal determinants of women participants' empowerment is the realization that women are unique people who are located within specific socially defined gender, ethnic, sexual orientation, age, ability and class spheres. Program developers must understand that it is impossible for one program to meet all of women participants" needs. Yet, efforts must be made to address commonalities that women may experience. HIV prevention and sexual health promotion program developers should consider the inclusion of program elements to highlight the prevalence and unacceptability of sexual victimization and coercion (Brunette and Drake). Comprehensive programs should sensitively highlight the ways in which "modern social organization creates situations where women have no control over the aspects that affect their life and work" and they should illustrate that "a disjunction between the world as women experience it and the terms given them to understand the experience" is often a determinant of women's mental illness, rather than a "dysfunctional" biology (Penfold and Walker 55). Issues of bereavement must also be addressed as women learn to replace self-defined harmful or "risky" behaviours with

healthy ones. If "sexual behaviour is a preferred means of socializing and attracting the attention of others," it is likely that women participants may fear that losing sexual partners will mean losing intimacy or attention (Friedrich and Grannon 262). Thus, it is expected that major lifestyle changes will elicit a grieving process with which women participants will have to learn to cope.

Lastly, it is essential that sexual health promotion programs continue to have an educational component. Even though current educational program are not as comprehensive as they could be, it is essential that women participants" self-perceived education needs be addressed in a way that coincides with the developmental process of empowerment. As women define their needs for information, it must be up to them and to the facilitating staff to collectively seek answers and strategies to questions and concerns. It is essential that women know and feel comfortable with information relating to their (and men's) bodies' function and pleasure. It is also important that women be provided with every opportunity to learn of HIV and STD barrier methods.

Although the development of a comprehensive sexual health promotion program with and for women living with mental illness will certainly be no easy task, it is possible. Rather than focusing on short-term programs that stress HIV/STD infection prevention, a more feasible longterm strategy is that which highlights the complex structural, emotional and physical issues experienced by women living with mental illness. To carry out such programming, professional staff must support the development of a genuine relationship between they and program participants that promotes power sharing and communicates mutual hope, dignity, and respect. HIV prevention and sexual health promotion programs must reflect the goals and values defined by the people receiving the program and support the external mandate for empowerment by providing information, opportunity, representation, and choice to all participants as they define the need. Comprehensive programs must also support the internal mandate for empowerment through discussion, feedback, and serious consideration of the perspective the person brings to decision-making and self-determination. Should such programming become the norm, it is possible that the mental health system could move a step closer to replacing hierarchy with participation and choice, enforced dependency with enhanced control, isolation with connection, models of pathology with models of recovery and strength, and objectification and a primarily biological model with an understanding of people as human beings interacting with each other and operating in a social context that has a vast influence on their behaviour and mental health (Kalinowski and Penney). It's certainly worth a try.

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'Although I will use the term "mental illness" throughout this essay, it should be noted that I have grave concerns about the primacy of psychiatric ideology and psychodiagnosis in our society. Increasing numbers of critics of psychodiagnosis highlight its use in the control and stigmatization of socially undesir-

able behaviour that is not really disordered (Wakefield). I understand that women are more likely to be labeled mentally ill than men and that the reaction to disturbed behavior in women is harsher given the pressure on them to conform to socially defined norms of femininity which are almost impossible to balance and uphold (Busfield). Because space does not allow for an in-depth critique of the concept of mental illness definition, for the purposes of this essay, I will define mental illness as "the failure of a person's internal mechanisms to perform their functions as designed by nature which impinges harmfully on the person's well-being as defined by social values and meanings" (Wakefield 373).

²Due to the large surface area of the vagina and the high probability of vaginal tearing during sex, man-to-woman HIV transmission is four times more efficient than woman-to-man HIV transmission.

³For this paper, I conducted a search of the Medline, AIDSLINE and Social Science Abstracts databases using the following key words: "women and mental illness and HIV prevention"; "women and HIV and education and mental illness."

Of course, the terms "safe" and "unsafe" relate in a simplistic way to the physiological safety of a sexual act (i.e. a "safe" act is one with a low probability of HIV or STD transmission). This does not necessarily relate to the emotional, mental or spiritual "safety" of a sex act. For example, the strict definition of a "safe" sex act could be an act of coerced sex with a condom. Such an act would not be considered emotionally, mentally or spiritually safe for anyone.

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