Communities of Caring: Integrating Mental Health and Medical Care for HIV-Infected Women
Kimberly Harris, PhD and Lori Demain Williams, LCSW

Models of women’s health care delivery that include significant provisions for mental health services are rare. Even rarer are models that are intentionally constructed to capitalize on the natural interaction between women’s physical and emotional health. But the repercussions of this interaction have led a few centers to adopt service delivery models that offer truly integrated, holistic care.

In 1988, the Women and Children HIV Program (WCHP) of Cook County Hospital’s HIV Primary Care Center in Chicago was conceived to respond to the burgeoning challenge of women and children with HIV disease. From its inception, the mission of the WCHP has been to practice a model of health care that is responsive to the culture of women as well as the culture of HIV. Applying a feminist perspective, the needs of women comprise the starting point, are the focus of advocacy, and govern the programatic and clinical direction. WCHP believes that the best models for providing care to women with HIV disease or who are at risk of infection are those that recognize that women’s access to and benefit from medical care is colored by socialized power constraints and a history of interactions with judgmental social, medical, and political systems.

Milieu Treatment

WCHP translates this philosophy into practice by providing each participant in the program with the opportunity to develop ever-broadening “communities of caring.” The core care community includes a seropositive woman, her family of birth and family of choice, sister program members, and her WCHP medical provider, health educator, case manager, and mental health practitioner. In this community, WCHP case managers assume the lead service coordination role for individual participants. This participant-provider grouping forms the nucleus for the delivery of medical services and the core unit for WCHP’s primary mode of psychological intervention: Milieu Treatment. Milieu theory holds that involvement in controlled, emotionally healthy environments can be beneficial preparation for healthier functioning in larger, less controlled environments.

WCHP has constructed an environment in which 80 professionals, most of whom are women, and 757 seropositive participants know each participant’s serostatus, respect whatever life events have sustained them up to this point, and form a network that will support each other’s continued growth. In this setting, applying a dynamic psychological treatment plan shaped by both participant and mental health provider, it becomes possible to develop, increase, or solidify positive self-esteem.

Only a few agents of emotional support for the milieu are on the formal mental health team. All the professionals play a role in maintaining the emotionally corrective nature of the milieu. The WCHP professional staff includes a range of specialties: medicine, nursing, case management, health education, child care, nutrition, pastoral care, and chemical dependency. The staff is intentionally diverse in terms of race, spoken language, sexual orientation, age, religion, and serostatus, mirroring the diversity of the participant population and increasing the likelihood that each participant will find someone who shares her experience and
Editorial: Crossing Disciplines
Robert Marks, Editor

Two years ago at the International AIDS Conference in Berlin, Carola Marte, a former FOCUS author and sometimes-advisor, told me about an amazing program in Chicago, a clinical program for women with HIV disease that had successfully combined medical and mental health care. Marte emphasized that this program was large—with more than 700 clients—and that its ability to respond to the emotional as well as the physical was particularly important to women but applicable to men as well.

A year later, Marte—a Yale University physician—and I were chatting again: she said that she was noticing more and more concern regarding "permanency planning," and the necessity to disclose HIV serostatus when planning for the future of children of parents with HIV disease.

I guess this is the "Carola Marte issue," one that examines two emerging approaches to the needs of women with HIV disease. But Marte would be the first to suggest that the "Communities of Caring" outlined by Kimberly Harris and Lori Demain Williams could be created in other HIV-related clinical settings, and that the permanency planning options described by Marybeth Kent Brazelton and Jean Lewis are also relevant to men.

An Interdisciplinary Approach
Perhaps the most fundamental principle underlying these two articles is not that women's care is different from men's, but that quality care is the result of an interdisciplinary approach. AIDS has pushed many programs toward strengthening the concept of the treatment team, consciously creating ongoing links among the many people involved in HIV-related care. But, it's one thing to allow for these connections; it's another to build an interdisciplinary approach into the foundation of a program.

Both the Women and Children HIV Program in Chicago and Legal Services for Children's HOPE Project in San Francisco acknowledge the connections among disciplines as being the central tenet of HIV-related care. It is this approach, and, in particular, the appreciation that a mental health component—an emotional aspect—pervades the more cognitive realms of medicine and law, that make these programs so compelling.

Ten Years of FOCUS
And now for a digression: it is serendipitous that I have mentioned Carola Marte here, because this issue of FOCUS marks the finish of our tenth year of publication. In December 1985, Jim Dilley, Michael Helquist, and medical consultant Steve Follansbee founded FOCUS, and over the past decade, they have nurtured it. But they and I would be the first to admit that it is only because of the input from people like Carola Marte and the contributions of hundreds of authors that FOCUS has been able to endure.

Applying Milieu Treatment as a therapeutic intervention, WCHP providers work with participants to construct a physical setting that offers support, containment, safety, involvement, and validation for participants. The medical clinic is the physical setting framing initial milieu interactions and is the structure at the heart of the WCHP care community. WCHP provides services to 80 percent of the known population of seropositive women and 35 percent of the known population of seropositive children in Cook County. Typically, 30 to 40 women and children have medical appointments at each clinic session. Providers make a concerted effort to match clinic appointments for members of the same biological family group to afford participant-mothers the practical benefit of fewer appointments and the psychological benefit of empowered participation in their children's care. At each clinic session, another 10 to 20 people may come in for unscheduled medical interventions. At any time, an additional 50 to 80 people may be present at the clinic, availing themselves of non-medical services, including support groups, health education sessions, or simply enjoying the safety and sisterhood of the milieu.

Psychotherapeutic intervention begins at intake, at which time participants experience the support of a community in which serostatus is no secret and there is no underlying discriminatory agenda. Participants are immersed in an informed and empathetic milieu that encourages them to provide not only for themselves, but also for each other.

At intake, women new to the clinic experience other participants as living models for coping with HIV disease. Every
participant in the corrective milieu becomes a potential model of coping not only with the physical manifestations of HIV, but even more so, with the life events HIV poses. The ethos of the milieu—instilled by all of the program's support groups—is one of sharing. Older members adopt newer members and help them understand how to live and thrive with HIV and in the program. The milieu itself, rather than the medical clinic alone, becomes a destination, a place where people go to support each other through groups, appointments with staff, and, significantly, informal connections with other members.

In this atmosphere, it is likely that a new participant will find sister participants who are effectively coping with the same challenges that dominate her life—chemical recovery, poverty, domestic violence, mental illness, and issues related to disclosure of serostatus—participants at every stage of political and social system savviness. By identifying women who share her emotional, physical, and social status, new participants have immediate access to practical models for growth. It is a tribute to this approach that members often visit the milieu even when they do not have formal appointments, some spending a whole day giving and receiving support and advice.

Involvement in the milieu increases the number of people in each woman's life who are invested in her well-being. Incorporating these living models into the milieu enables every participant to be both "mentor" and "mentee."

Integrating Mental Health

The role of the formal WCHP mental health team is to facilitate the adjustment of women to the milieu and to act as resource personnel for issues that escape natural resolution in the milieu. Staying true to the intent of the original model of a core service provision unit, the WCHP has dedicated significant resources to mental health care in what is essentially a primary care setting. The team consists of three psychologists, two psychiatric social workers, an art therapist, and four consulting psychiatrists. Participants are linked to one of the mental health providers but over time are free to form therapeutic alliances with any of the other providers.

It is likely that seropositive women presenting for primary care will be wary of seeking out mental health care. The active participation of the mental health counselors within the interdisciplinary core provider unit normalizes much of this anxiety. Counselors seek to form relationships with clients and to maintain these relationships, at minimum, at every medical appointment. They address pre-diagnosis mental health issues, prepare psychological testing reports, and facilitate psychopharmacological referrals. They also provide counseling for the women and their seropositive and seronegative families and friends through outpatient or telephone sessions, inpatient bedside visits, and home visits. Finally, they offer grief counseling to survivors. WCHP offers on-site support groups for seropositive women, partners, children, adolescents, and caregivers. By actively welcoming the people who are important to participants into the interventions, the milieu approach seeks to deepen the familial resources available to clients.

WCHP counselors tend to become more intensely involved with participants at predictable points during the course of HIV disease. These psychological crisis points include: diagnosis, diagnosis of a partner or child, change in diagnosis from HIV infection to AIDS, the first time antiviral therapy is prescribed, the first hospitalization, the death of a family member, and the death of a prominent milieu member. During these crises, WCHP medical providers are as likely as participants to seek emotional and psychoeducational support from counselors.

Experience has taught the mental health team that as overpowering as such HIV-related issues can be, they may not be as insistent as pressures associated with being female, being a racial minority, or being without social and economic power. The team's mode is to respond holistically; to become involved with participants as they deal with the criminal justice system, the child welfare system, the public schools, and chemical dependence centers, as well as with HIV-specific crises. If the ultimate goal is to encourage women to lead full lives, the mental health
provider must be prepared to be an advocate in every arena women enter. Any time a professional enters a larger system on behalf of a particular woman, the woman benefits, and the entire community of women benefits from the work of these trailblazers.

With consultation from the formal mental health team, WCHP staff members from every discipline are involved in esteem-raising activities. WCHP providers run classes for clients leading to certification in parenting, peer HIV counseling, and peer drug counseling.

The Larger Community

A larger concentric care community includes liaisons from Chicago community service agencies. Present at most clinic sessions are representatives from legal and utility assistance, social entitlement programs, domestic abuse agencies, and alternative therapy (acupuncture, massage) providers. These liaisons, although not WCHP employees, share WCHP’s mission for woman-centered care. They form an important transition group that allows members to pursue their own service plans as they gain confidence while still in the controlled safety of the milieu.

The milieu continues to broaden as seropositive and seronegative adult and adolescent peer educators trained in WCHP classes solicit and accept opportunities to speak about HIV prevention and treatment in the wider community. The personalized experience peer educators provide to their audiences typically results in effective outreach for HIV antibody testing and counseling. Just as important, peer educators increase HIV literacy and compassion in the groups they visit. Speaking opportunities enable WCHP participants to test their increasing confidence and self-esteem outside the milieu and in situations in which they are likely to be challenged to affirm themselves.

Conclusion

There is evidence that milieu treatment is an effective model of psychological intervention in the medical venue. For example, the 20 percent of participants who are most involved with the milieu are more likely to maintain their medical appointments; enter, stay longer, or complete drug treatment programs; and regularly employ safer sex practices. More than 50 percent of participants reporting depression, anxiety, and other psychiatric symptoms, experience consistent decreases in symptomatology once they become active in the milieu. When queried about the significant positive influences in their lives, more than 80 percent of participants report that the support of the milieu has been pivotal. Social service agencies report that the milieu has led to improved parenting practices and enabled a number of women to maintain or regain custodial ties to their children. Finally, 10 percent of women in WCHP resume their education or gain employment for the first time.

In sum, women who are empowered in the milieu become the most proficient advocates for themselves, their families, and other seropositive women. The best psychological intervention for individual seropositive women is one that improves the circumstances for all women, a program that fosters ever-broadening, informed, and caring communities.
Permanency Planning for HIV-Affected Children
Marybeth Kent Brazelton, EdM and Jean Lewis, JD

According to recent statistics, as many as 125,000 children in the United States will lose their parents to AIDS by the year 2000. Developing plans for the care of surviving children is crucial for the mental health of both the child and his or her dying parent. This article provides a brief overview of “permanency planning” options currently available to HIV-infected families and raises issues typically encountered during the process. *

Permanency Planning Options

Several options are available to terminally ill parents planning for the future care of their children. Because HIV disease often results in periods of incapacity followed by periods of relative wellness, standard options that require permanently giving up custody during their lifetime are often not used by HIV-infected parents. For example, adoption results in the termination of the biological parent’s rights and the substitution of a new parent. Conventional guardianship, while short of adoption, suspends a parent’s custodial rights and assigns these rights to a non-parent.

In response to this predicament, two variations on conventional guardianship have been developed in different states. The first, “standby guardianship,” allows a parent to nominate a non-parent to assume complete custody of the child upon the parent’s death or incapacitation.

The second, “joint guardianship,” allows a terminally ill parent to nominate one or more people to share the custody of her children. This arrangement permits equal sharing of rights and responsibilities until the death or resignation of one of the joint guardians (which includes the parent), at which point custody continues with the remaining joint guardian(s). These new mechanisms are particularly well-suited to HIV-affected families, since they allow terminally ill parents to formulate legally enforceable plans for the future care of their children while permitting them to retain custody while they are living.

A third variation, which is not in use at this time and requires investigation, may suit a parent with no potential guardians. A hybrid arrangement—joint guardianship with an adoptive family—this approach would allow the parent to maintain parental rights while preparing for eventual adoption upon death. It would, however, require patience and perseverance on the part of both birth and adoptive parents as they work to develop relationships with each other and with the child.

While choosing among these options will depend in large part on a parent’s willingness to share or relinquish custody, it will also depend on the identity of the future custodians. Most successful permanency plans formalize, to some degree, a family’s strengths and the care arrangements that are already working for the family. Providers should listen carefully as parents identify the players in their current support system and their hopes and fears for the future. They should also explain the criteria a court is likely to consider when making a guardianship ruling. Primary

*While permanency planning may be an issue for both male and female parents with HIV disease, single mothers—and usually impoverished single mothers—are most likely to face this dilemma. This article focuses in particular on their concerns.

See also references cited in articles in this issue.
Most successful permanency plans formalize a family’s strengths and the care arrangements that are already working for the family.

Disclosure

The greater challenge often lies in confronting the psychosocial issues—most prominently related to disclosure—that are likely to arise during the exploration of guardianship options. Effective permanency planning requires that the parent and the family have a fairly advanced level of acceptance of her disease and an awareness of her impending death. In addition, the parent’s attorney has a duty to notify certain people before executing a guardianship or adoption. Among these people are the child’s other parent, maternal and paternal grandparents, and siblings.

Guardianship issues usually arise when the parent is in the late stages of disease, making it likely that most potential guardians will know about the client’s illness. Nonetheless, disclosure may raise issues of denial and secrecy. Providers must respect denial and its value in insulating a parent from information she may not yet be ready to handle. As part of this process, providers should undertake an assessment with the parent to determine who in the family or community knows about her diagnosis and who needs to know in order to formulate a viable plan. In an effort to help clients discuss HIV disease with potential guardians and their children, providers should be prepared to intervene with age-appropriate educational materials and counseling services. At a certain point, however, a parent may have to make a choice between denial and secrecy and plans for the future care of her children: permanency planning may be an effective tool to use to begin this process.

Providers must acknowledge the reality of HIV-related stigma and the ways in which it may compound denial and lead to secrecy. The real possibility of ostracization and isolation may raise the price of planning. Since HIV carries more of a stigma in certain cultures than in others, the cultural background of the family is also a crucial factor in a parent’s decision whether or not to disclose their HIV status.

In an effort to make the idea of disclosure less threatening, a provider can help prepare a parent by educating her about her options, including reviewing the services available such as support groups, counseling services, and financial resources. A provider can help the parent explore the potential psychological benefits of disclosure such as being able to talk freely to her children, opening new avenues of dialogue, and deepening existing relationships. Ultimately, disclosure even to family members is an intensely personal decision and the benefits of planning for the future must be weighed against the potential disadvantages a parent might encounter.

Conclusion

Permanency planning helps avoid the needless placement of children in foster care and the resulting financial and social costs. When successful, permanency planning is a tool providers can use to strengthen family relationships and to develop a safety net for HIV-infected parents and their children. It offers parents a tangible means of managing some of the impact of AIDS on the family and leads to the identification of sources of support that can minimize the disruption following a parent’s death.

References


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Linking Mental Health and Primary Care


An evaluation found that by using non-mental health professionals to provide mental health services, the federally-sponsored Linkage Programs integrate substance abuse treatment and primary care, maximize their resources, and lead to better mental health care.

Sponsored by both the Bureau of Primary Health Care and the National Institute on Drug Abuse, the Linkage Programs are 21 community-based care systems in various states. In each program, a lead agency, such as a medical center or health department, serves as a base for linking primary care and substance abuse treatment providers in the community. The clientele of each Linkage Program consists primarily of low-income and ethnically diverse populations.

While not initially designed to incorporate mental health services, the programs found these services to be in demand for a high proportion of their clients. Collectively, the programs reported that 6 percent of their clients had a severe mental illness, 28 percent had moderate mental disorders, and 37 percent had minimal mental health problems.

The Linkage Programs provided both extensive referrals and on-site mental health services, ranging from assessment to hospital in-patient treatment. The evaluation found that in all the programs, individual counseling—the most time- and labor-intensive service—was also the most frequently used. Confronted with an overwhelming demand for these services, a limited capacity to provide them, and the alienation of many clients from traditional mental health providers, Linkage Programs used non-mental health professionals such as primary care physicians, nurses, substance abuse counselors, and case managers to provide counseling, crisis stabilization, and assessment. The programs provided training, both formally through certification and continuing education credits, and informally through multidisciplinary teaming and case conferences, to ensure the quality of these mental health services.

Assessing HIV Risk in Women


A survey of 17,619 women in primary care found that 14 percent are at high risk and 44 percent are at moderate risk for HIV infection. Women over 24 years old and Black women were at highest risk for infection.

Participants were recruited at their health care sites in a large northeastern city: 52 percent White, 42 percent Black, 5 percent Latina, and 1 percent of other origins. The mean age was 23 years old, and 77 percent were unmarried or not living with a partner. Most of the women (70 percent) had a high school education, and 77 percent had low incomes. Participants reported risk factors for HIV infection, condom use, and previous HIV antibody testing.

The most common risk behaviors reported for the 14 percent of women in the high-risk group were having more than two sexually transmitted diseases (STDs) in the past five years (38 percent) and having had sex with an injection drug user (35 percent). Of the 44 percent of women in the moderate-risk behavior group, 85 percent had between two and five sex partners per year since 1978.

Black women were more likely to have a greater history of STDs, and White and Black women were more likely to have had multiple sex partners than Latina women. Women over 24 years were about four times as likely to have had sex with an injection drug user or bisexual male than women under 20 years.

Only 12 percent of the women reported they always used condoms, 31 percent sometimes used them, and 52 percent had not used them at all in the past six months.

Survival rates among women with HIV disease are comparable to those of men.
Older women and women of color were less likely to use condoms consistently. Ninety-three percent of the subjects had not undergone HIV testing.

**HIV Progression in Women**


A longitudinal analysis of 82 women in clinical care found that *Candida* esophagitis and *Pneumocystis carinii* pneumonia (PCP) were the most common AIDS-defining conditions, and survival rates were comparable to a similar study of men.

The sample was ethnically diverse, with 48 percent White, 40 percent Black, and 12 percent Hispanic. Transmission routes included 59 percent heterosexual contact, 22 percent injection drug use, 10 percent blood product transfusions, and 8 percent had unknown risks. At the time of admission, T-helper cell counts tallied below 200 for 33 of the women. Of those, 14 had AIDS, 17 were symptomatic, and two were asymptomatic.

The most common initial HIV-related symptoms were due to *Candida* infections including oral, esophageal, and recurrent vaginal; at follow-up, 56 percent of women had some form of candidiasis. The median time to progression to an AIDS-defining condition was 57 months, and the median survival after AIDS diagnosis was 27 months. This survival time was comparable to the 26 month longevity after an AIDS diagnosis of PCP among men in a cohort study in 1990-1991.

One new finding from the study was that participating in a clinical trial significantly improved the length of survival time. The 34 women who participated in antiviral clinical trials had a median survival of over 59 months compared with 39 months of nonparticipants. Since clinical trials do not select subjects randomly, however, there are confounding elements that contribute to this difference.

**Taking Care of the Children of HIV**

Schable B, Diaz T, Chu SY, et al. Who are the primary caretakers of children born to HIV-infected mothers? Results from a multisate surveillance project. *Pediatrics.* 1995; 95(4): 511-515. (Centers for Disease Control and Prevention; and 10 local or state health departments.)

A large multi-state survey found that most HIV-infected mothers are the primary or sole caretakers of their children. Despite the vast array of social and health-related issues faced by these women, less than one-third know about child care assistance services, and only 8 percent have contacted or used these services. Researchers theorized that women underutilized services because they feared losing their children.

All women with HIV or AIDS reported to 10 state and local health departments were contacted and asked to be interviewed if they had a child born after 1978. Of the 478 mothers surveyed, 85 percent were unmarried, 88 percent were unemployed, and 72 percent had an annual household income of less than $10,000. One-third of the children were under the age of five years old, and the oldest ones were 15 years old.

Overall, 46 percent of the women were the primary caretakers of their children, while 16 percent reported that grandparents and 15 percent reported that both mothers and fathers took care of the children. Although women exposed to HIV through injection drug use were less likely than women exposed by other means to be the primary caretakers, very few had given up their children to foster care, a finding that contrasts with previous studies.
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