HIV Mental Health for the 21st Century

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Published by NYU Press

Winiarski, Mark G.
HIV Mental Health for the 21st Century.
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People who make me feel like a normal person, who are not afraid of me because I have HIV, who treat me with respect, who give me love, support, and friendship.

— Common responses to a survey that asked fifty women, enrolled at the Helena Hatch Special Care Center, what they need from a center for women who have HIV

For HIV-infected women, HIV/AIDS is at the nexus of who they are in society—daughter, mother and mate—how they are positioned in society—in terms of power and control over their own lives—and who they are within themselves. To care for them cannot simply be a biomedical task. HIV/AIDS caregivers must care for the entirety of a woman’s being.

While programs of the early epidemic focused primarily on white gay males (Novello, 1993; Rosser, 1991), the increasing impact of HIV disease on women has necessitated a rethinking of our response to the disease (Health Resources and Services Administration, 1995).

Through June 1996, the Centers for Disease Control and Prevention reported 78,654 AIDS cases in adolescent and adult females in the United States. This represents 14.5 percent of this country’s cumulative total of AIDS cases in these age groups (Centers for Disease Control and Prevention, 1996). It is among the leading causes of morbidity and mortality in women, especially those of childbearing age (Centers for Disease Control and Prevention, 1995; Quinn, 1995).
**Background Reading**

HIV disease has disproportionately affected minority and disenfranchised women, many of whom are unmarried mothers and poor, with low educational levels (Chatters, 1993; Quinn, 1993; Schneider & Stoller, 1995; Shayne & Kaplan, 1991; Shelton et al., 1993; Ward, 1993; Ybarra, 1991). Many engaged in high-risk behaviors such as injection drug use or unprotected sex with multiple partners. Others, however, were not aware of the risk of infection, having had sex only with a partner or spouse who had not disclosed, or denied, being HIV positive (Novello, 1993).

Our experience corroborates the literature on the counseling needs of women in general, as well as those that are specific to women with HIV. Because of the demands of women's multiple roles, as daughters, mothers, and mates, women often overlook their own mental and physical health requirements (Minkoff & DeHovitz, 1991). Numerous authors have shown that women have a need for connection and intimacy with others in order to feel their own sense of value (Gilligan, 1982; Jordan, Kaplan, Miller, Stiver, & Surrey, 1991; Miller, 1986). Preserving a relationship, even an abusive one, may be a primary concern, with consequent subjugation of the woman's own sense of self and personal needs.

The stigma attached to having HIV can make disclosure difficult for women, particularly because they fear rejection by people who provide important relationships. On the other hand, keeping their serostatus a secret can lead to a torturous form of isolation (Miller & Goldman, 1993; Pizzi, 1992). A woman's self-image can be destroyed by the diagnosis; she may feel "sexually dirty and unloved" and, as a result, may withdraw from future relationships (Ybarra, 1991).

The issues surrounding reproductive decisions are significantly complicated by HIV. Giving birth to a child can meet biological, social, and self-esteem needs, foster a relationship, and offer a sense of future to the mother (Lee, 1995). Despite this, there can be great psychological conflict over the chance of transmitting the virus to her child and her partner. Although recent findings of the study known as ACTG 076 (Centers for Disease Control and Prevention, 1995) showed a reduced risk of perinatal transmission when pregnant women and their newborns took zidovudine (ZDV, also called AZT or Retrovir), women face the sobering fact that their children still may be infected and that the children may be motherless at a young age. In addition, women must consider how they will be able to manage the daily demands of motherhood as they become more ill
In addition, women have to face providers who may be confounded and angry at an HIV-positive woman's decision to get pregnant, resulting in unavailable or inadequate counseling and support (Ward, 1993). Finally, the woman faces depersonalized and unwieldy health care and social services systems, compounding her lack of control over her care and fate.

Several panels of experts have defined the need for providing accessible, coordinated, comprehensive, family-centered, and culturally sensitive care for women infected with HIV (Health Resources and Services Administration, 1995; Shelton et al., 1993). Several such projects have been created, including ours, and as of this writing the HIV/AIDS literature has just begun to report their practice (Harris & Williams, 1995).

**Our Clinical Practice**

The Helena Hatch Special Care Center serves HIV-infected women who reside in metropolitan St. Louis, a twelve-county area within eastern Missouri and southwestern Illinois. At least three quarters of our enrolled clients are African American and unmarried and live in poor, urban settings. The majority fall in the twenty-one- to thirty-year-old category, and 43 percent care for at least one child.

Our center offers primary and specialty medical care as well as psychosocial support and case management in a one-stop-shopping environment, meaning all services are available at one site. Less than nine months after we opened, our enrollment had increased from 43 to 106.

Before the individual attends clinic for the first time, our social worker meets with her and conducts a psychosocial assessment. Usually this meeting takes place in a nonclinical setting of the client's choosing, such as the home, a restaurant, or even a street corner.

When the client arrives at the center, the social worker is there to meet with her, helping to establish a sense of trust and continuity. The social worker also serves as a Ryan White services coordinator, providing access to community resources that might not be available at the center. Women may present with symptoms of depression such as sleeplessness, lack of appetite, or feelings of inadequacy. The clinical social worker addresses mental health needs by making an assessment; the social worker and nurses then provide basic ongoing psychosocial support. If the woman's psychiatric situation is sufficiently serious, referral is made to various
community mental health programs and, if necessary, inpatient psychiatric services. Unfortunately, compliance with referrals off-site is low; patients seem to prefer services that are provided within the center, and that fact increases our staff's sense of responsibility in caring for the woman *in toto*.

The center's nurses provide clinical management of the client, which includes providing education about the condition and its treatment, offering reminders about upcoming appointments, and allaying fears at the various transition points of the illness. The entire interdisciplinary team, including physicians, social worker, nurses, dietitian, chaplain, and OB/GYN nurse practitioner, meets regularly to share information and recommendations about each client.

In working with women, we find it important to understand whom they identify as their families. Issues regarding children and role responsibilities must be addressed before we can tackle areas regarding HIV/AIDS. In other words, if a client is most concerned about how to get formula for her infant, while the clinician is addressing safer sex issues, both parties will end up frustrated. Women usually put their families first before they attempt to meet any other needs. Our providers strive to hear the woman's messages about what comes first in her life, thus meeting her "where she is," through family-centered, coordinated care.

We invite consumer suggestions so that we can tailor the program and policy decisions to client needs. We have involved clients in focus groups, interviews, and surveys. Our center also has a community advisory board, which meets quarterly to provide input into programmatic decisions. Our clients tell us we must address the issues of confidentiality, safety, child care, and transportation.

Our mental health services are illustrated by our work with Mary, a young mother of five boys. She has known of her HIV infection for four years and likely was infected by her first husband, who died four years ago. None of her children is infected. Mary is undergoing divorce proceedings with her second husband, who is not the father of any of the children. He is seronegative and has had difficulty accepting her HIV diagnosis. He also is feeling overwhelmed by the thought of taking responsibility for her children after she dies.

The center's social worker has followed this family since the birth of Mary's fifth child. She provided emotional support and counseling to Mary during the anxious months of waiting to learn the child's HIV serostatus. During that six-month period, Mary dealt with her feelings of
guilt about possibly infecting her child. She expressed constant fear about how she would be able to care for herself as well as for a sick child.

Mary has had symptoms of depression for the past five years. Despite numerous referrals for psychiatric treatment, she has not sought outside services. Yet, she has attempted suicide twice and continues to struggle with guilt about her infection and “leaving her five boys.”

Our social worker has provided counseling sessions to Mary and her husband to help them consider the various issues surrounding their marital conflict and their parenting roles. She assisted Mary in permanency planning for her five children, since they will be orphaned after her death. She also served as liaison with legal aid services in the divorce action and in arranging legal guardianship for the children.

Permanency planning is an issue addressed with all women followed by the center. The process may take years for many women and days for some. Regardless of symptoms, women are encouraged to address this issue with their support systems and eventually to follow up with community-based legal services. The agencies will assist with and file the legal paperwork necessary for a woman to complete this process.

At our center, Mary has completed an eight-week Steps to Living educational support group program where she developed relationships with other women in similar circumstances. We worked with the local chapter of the American Red Cross to bring to the center this program, which provides the structured environment needed for a sense of security and purpose and the camaraderie so needed by HIV-impacted women and their families.

The program offers a series of speakers who provide information about coping with issues related to HIV, such as contraception, HIV prevention, legal services, and spirituality. Most of the facilitators and speakers and many of the issues addressed are Afrocentric, since the majority of participants are African American. Participants include not only the women but also their caregivers (e.g., their mothers or partners). Following each educational session, there is an hour of support group interaction, one for the clients, another for the caregivers. Our center addressed barriers to participation by scheduling the program at a convenient time, offering a free dinner to attendees, arranging transportation, and providing on-site child care.

Mary continues to see the other women by attending biweekly support group sessions for program “graduates.”
Barriers to Dealing with HIV in Women

Barriers we have encountered include:

- **Denial of HIV infection or avoidance of discussion related to it.** This can occur early in the disease process when the client has few or no physical symptoms. The concept of being infected is too terrible and intangible to accept. To many women, being diagnosed with HIV, regardless of symptoms, means that they are going to die.

  Some feel the infection doesn’t exist if they don’t acknowledge it and therefore are noncompliant with medical care or do not make long-term plans. A few women have reported that seeing the members of the center is a constant reminder of having HIV. Long-term planning is very difficult when the client is in this stage. When timely, such planning may include such topics as permanency planning for children, setting up a will, establishing a durable power of attorney, and securing basic adequate housing and entitlements.

- **Fear of disclosure.** Most women show care and deliberation before revealing their HIV status. Because of this, they may avoid attending clinic or support groups that are openly for persons with HIV or where staff are members of their own community.

- **Poverty and chaotic lifestyles.** Many women we serve are poor, homeless, and engaged in substance abuse and/or prostitution. Meeting basic physical concerns takes precedence over entering into therapeutic relationships and focusing constructively on psychosocial needs.

- **Conflicting interpersonal demands.** Women, regardless of their HIV statuses, often have difficulty sorting out their own needs from those of others, such as their children, parents, partner, and peers. This can create problems when they need to allocate time and resources. It can also interfere with making difficult decisions, such as planning for the future, deciding to practice safer sex (Rosser, 1991), or choosing whether to get pregnant.

- **Low self-esteem.** Often women who engage in risky behaviors do so because of low self-esteem. Learning that they have HIV infection reinforces their sense of worthlessness and adds to their feelings of isolation and rejection. A history of abuse can be a
cofactor in this situation. In a recent survey of sixty-nine women, predominantly African American and white, at our center, 53 percent reported some form of sexual or physical abuse.

- **Entering into care late in the disease process.** A client may not realize that she is positive until she experiences the symptoms of AIDS, or she may have been tested earlier but chose to deny the infection because she was feeling healthy. Regardless of the reason, seeing a new client late in the disease can be challenging to the counselor if the physical demands overshadow the emotional needs. In addition, the client may be experiencing AIDS Dementia Complex, making it difficult for the counselor to understand her baseline personality.

- **External locus of control** (deCharms, 1980; Deci, 1980). If the client is impoverished and has lived within the realm of the welfare system, she may have little sense of internal power and control. She may not be accustomed to making her own decisions and to thinking far into the future. Rather, she may merely follow the directions given to her by those who make “the rules.” She also may be unable to negotiate safer sex with a demanding partner or to work through the difficult decisions of making terminal care plans.

**Tools for Clinical Practice**

We follow these principles in our work with HIV-infected women:

- **Self-empowerment must be a theme when counseling the HIV-infected woman.**

  HIV infection can force the individual to prioritize her personal goals. Ironically, this may provide her with a major impetus to take some control over her life. With the proper assistance, she may learn to make decisions that are best for herself, take charge of what will happen to her children, and learn skills that otherwise might not have been gained. Many clients are able to find a new inner strength and an appreciation for the essential beauty of life. The provider can facilitate this process through careful assessment, guidance, and concrete opportunities for the client’s growth.

  We have found three components to be helpful in promoting our clients’ sense of self-efficacy:
1. *Education.* The client must have adequate information in order to be able feel in control of her own decisions. To optimize the experience, the provider should regularly assess the client's stage of acceptance and personal informational needs. This can occur using a formalized assessment instrument, as we are using, or informally, by asking the client, "What questions do you have at this time?" or "Are there specific skills that might help you work through this situation?" It is critical that the counselor take into consideration the literacy, educational level, and learning-style preferences of the client to properly tailor the interventions. For one individual, videotapes along with one-on-one counseling may be the best course of action. For another, it might be group skill-building sessions with take-home written materials. We have found *AIDS: A Self-Care Manual* (AIDS Project Los Angeles, 1989) a useful reference for our clients. Family members and caretakers should be included in the educational process for reinforcement and to ensure continuity if the client becomes too ill to care for herself.

In some cases the education might take place in the home setting, which can enhance the level of comfort. Most important, the best education occurs when the messages are repeated and provided in a multidimensional fashion.

2. *Networking.* No matter how skilled the professionals involved, the affected woman seems to gain the most understanding by interacting with someone else experiencing the same situation. Many women with HIV/AIDS find it beneficial to meet others who have the same condition. This can occur through the development of a "buddy system" whereby two women get together in person or by telephone or more openly in a social or support group. The latter works best if there is at least one trained professional or peer facilitator who can watch for signs of severe discomfort or uncontrolled negativity in the group process. Women with similar problems can work together towards a positive synergy, thereby fostering a sense of power in resolving their own personal issues.

3. *Consumer advocacy and self-efficacy.* A real sense of empowerment can be fostered by involving the client in all phases of a program's implementation. At the most basic level, this
means including the client when her clinical and psychosocial care plans are being developed. This can occur by having the client (and if she wishes, family members) sit around the table with members of the care team to discuss her health status and treatment options. Regardless of the venue, it is important that the client have an opportunity to ask questions and receive honest answers about her condition. When decisions are to be made, the client should have enough information and support to make them for herself, knowing that the team will endorse her wishes.

- **Treat the woman within the context of her family unit.**

  Rarely does a client present herself as a separate entity. Most are involved in a personal relationship, some more permanent than others. Often when it comes to coping with a life-threatening illness, the affected person returns home, where there is a greater sense of acceptance and security. In many of our women's cases, this often means taking up residence with her mother, who may end up caring for her grandchildren when the mother is no longer able to do so. Sometimes, if the individual is married or in a long-term relationship, she and her partner may hold the information about HIV to themselves, fearing that they might in some way burden their family members with the news.

  It is important for the counselor to understand the composition of the family and the dynamics of the relationships. Sometimes it is helpful to use a genogram in order to work with the client in identifying who knows about the diagnosis and how prepared each is to assist with her or her children's care. This analysis is never static and must be reconsidered frequently. It is important to realize that family member roles may be nontraditional. For example, a lesbian lover may care for her sick partner's children, or a distant aunt may provide home care (such as giving injections or changing dressings) for the woman who is ill, while the mother may want to prepare the meals.

  In some situations, the male partner or husband may decide to take full responsibility for caring for both the infected mother and any children. In such a scenario, this might mean taking a leave of absence from his work, which might require enrolling in Medicaid.
Because women often place their care needs last, encourage a client to "listen to her body and her psyche."

One client explained that she had to be the strong one in the family as her husband was having difficulty coping with AIDS-related symptoms. She had grown up with a physical disability and said she was accustomed to dealing with this type of adversity. At the same time, she expressed a certain weariness at not being able to care for herself fully in this relationship. It is important for the counselor to offer the woman encouragement to listen to her body and her psyche and to help her sort out her needs from those of others. Concrete suggestions might be helpful, such as providing the client with an attractive blank book in which she can keep a journal. The Woman’s Comfort Book: A Self-Nurturing Guide for Restoring Balance in Your Life (Louden, 1992) provides a variety of innovative, individualized ways for women to care for themselves. We have several copies on our reference shelf for loan and have used its ideas when working with our women.

Understand the client’s culture.

Regardless of the ethnic, socioeconomic, or other group to which a client belongs, she exists within a particular culture that has its own context for understanding HIV/AIDS (Bevier, Chiasson, Hefferman, & Castro, 1995; Flasketud & Rush, 1989; Randall-David, 1995, 1989; Wofsy, 1995). The counselor should understand the nature of that environment from the standpoint of how the client receives information, what has value, and how certain actions by herself and by her care providers are perceived. This requires patience, sensitivity, and observation on the part of the counselor (see chapter 6).

Culture is identified not only by race or religion but by how the family unit uses that information within its context. An example is the topic of spirituality. Most of our women believe in a higher power. Delivering services effectively means that the clinician needs to identify the woman’s spiritual belief even if that clinician does not personally share that same religion or philosophy (see chapter 4). Prayer after support groups and disclosure at church are issues for many HIV/AIDS-affected women.

Use the “stages of behavior change” model to understand and intervene with clients who continue risky behaviors.
It can be frustrating for the counselor to work with clients who continue behaviors that put themselves and others at risk for infection. Thinking about the client in terms of "stages of behavior change" can be helpful to practitioners (see Prochaska, DiClemente, & Norcross, 1992; McConnaughy, DiClemente, Prochaska, & Velicer, 1989). The authors categorize clients into one of several stages: precontemplative, contemplative, ready for action, action, and maintenance. Each stage describes how the client views a "problem" and requires a different response and intervention. A client in the precontemplative stage, for example, believes she has no problem, although the clinician may think otherwise. A clinician’s response to a precontemplative client may be simple assurance that she may return for counseling anytime. A provider who fails to perceive that a client is precontemplative and continues to pressure her for a change only ends up feeling impotent and frustrated.

When the client shows readiness, the counselor can then provide interventions that are consistent with the client’s stage of behavior change. Someone in the contemplative stage may need further nudging regarding the problem; a client in the action stage requires concrete helping steps to resolve the situation.

- **Reproductive issues are a major issue when working with women.**

Many women discover their HIV status during pregnancy. HIV-positive serostatus usually comes as an enormous shock and brings subsequent feelings of guilt and fear that the unborn child may become HIV-positive. Other women, not yet pregnant, may desire to bear a child even if they already have an infected child.

Despite new scientific information regarding the use of zidovudine, reproductive issues are always complex. Without special antiretroviral intervention, the rate of vertical transmission, from mother to fetus, is between 13 percent and 30 percent. In AIDS Clinical Trials Group (ACTG) 076, zidovudine therapy was given to women with T-helper cell counts greater than 200 after the fourteenth week of pregnancy, during labor and delivery, and to infants after delivery. In the group that received the therapy, vertical transmission was 8 percent compared to 25 percent in a placebo group (Centers for Disease Control and Prevention, 1995; Kurth, 1995). How effective the therapy will be in the general HIV-infected population, in women with different levels
of adherence, and especially in women with advanced disease, remains to be learned.

We see a couple in which the wife is infected but the husband is not. They have a child who is terminally ill with HIV/AIDS. After careful consideration, they decided to conceive another child because the husband would like to have a healthy child after his wife and his first child are gone. They are using artificial insemination to protect him from infection. This and other complicated situations regarding childbearing are quite common among women with HIV.

The counselor can play a pivotal role in assisting the client in making an active and informed decision about whether she wants to have a child (Hutchison & Shannon, 1993). The provider can discuss the advantages and disadvantages, the risks and benefits. Issues to discuss are:

1. Reasons for having the child. Sometimes the client herself is unable to clarify this.
2. Plans for care of the child when the mother is too ill and after her death.
3. Personal behaviors that can decrease risk of transmission and contribute to having a healthy baby.

These discussions must be done in a nonjudgmental, nondirective manner, with respect and assurance of continuation of care regardless of the decision. This is easily said but may be difficult in that the provider may have a certain opinion on the subject at hand. Our judgments are best kept to ourselves, lest we recapitulate a situation that women have faced all their lives: someone else attempting to be in control and to force decisions on them. Our task is to care for women and their families, not to direct their lives.

**Conclusion**

At the Helena Hatch Special Care Center we feel we succeed in building relationships when the women return for care. And for us, care extends beyond the biomedical. Women may seek our assistance in resolving housing issues or obtaining food. We have created a nonjudgmental, accepting atmosphere in which the women feel welcome, where issues
can be discussed by the women without their feeling ridiculed or embarrassed by their lack of knowledge. Women come to the center for clinical care and take much more than that home with them.

REFERENCES
This chapter was supported by Grant Number BRH 900125-02 from the Health Resources and Services Administration. The opinions expressed are those of the authors and do not represent those of HRSA.


