HIV Mental Health for the 21st Century

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HIV-affected clients in the inner city present with a Gordian knot of biopsychosocial and spiritual problems. For many, HIV is just one more strand in the knot that already includes medical problems such as diabetes, asthma, and hypertension; emotional disturbances; substance abuse and dependence; chaotic and violent living situations; and lack of resources (Gellin & Rodgers, 1992; Leukefeld, 1989; McKenzie, 1991).

For these individuals, medical needs most often take priority over mental health issues. Even if they recognize the need for mental health assistance, too many of them lack the energy to negotiate yet another treatment system and fail to get the help they need (Furstenberg & Meltzer Olson, 1984).

In this tangle, three issues stand out:

1. Like others struggling to cope with other catastrophic illnesses, HIV-infected individuals receiving medical care frequently do not view mental health services as a way to obtain help to cope with what is happening to them. Generally, they see themselves as being physically ill, not emotionally disturbed or mentally ill.

2. They fear being labeled "crazy," being condemned if their lifestyles are known, or being isolated and discriminated against if their diagnoses are disclosed.
3. The lack of stable housing, child care, transportation, and financial resources all act as barriers to care.

Women, who represent an increasing percentage of HIV-infected individuals, particularly among the urban poor (Altman, 1994), face additional barriers to mental health services. While they are more likely than men to use mental health services in general, HIV-infected women tend to avoid even medical treatment until late in the disease process, and they often do not access mental health treatment at all (HDI Projects, 1995, 60). As caretakers for their children and their partners, often they put themselves last (Wofsy, 1987). In our experience, other reasons for not seeking help are their feelings of shame and their lack of trust in the health care and the social service systems—they fear that they might be judged on their childbearing decisions or lose custody of their children if they admit that they have problems by seeking help. (See chapter 16 for additional information on care for women.)

People with substance abuse problems remain a treatment conundrum. They are caught in a fragmented system that supports their denial that their substance abuse creates or contributes to problems (Hazelden Foundation, 1993; Johnson, 1980). This denial may prevent them from seeking either mental health or substance abuse treatment. Mental health providers are hesitant to treat substance abusers because they feel unqualified and because they doubt the efficacy of mental health treatment undertaken before substance abuse problems have been addressed. Substance abuse treatment professionals prioritize substance abuse detoxification and rehabilitation as the basis for any other treatment (Evans & Sullivan, 1990), and medical care providers are frustrated by compliance issues.

Background Reading

Through our experience treating HIV-infected people, we have come to a growing awareness of the interrelatedness of clients' problems and of the way that existing systems of care have failed to recognize this interrelatedness. Our clients have multiple medical appointments, multiple overlapping stressors, and limited energy. The need to negotiate multiple systems while facing the threat of fatal illness has been overwhelming for them. Service delivery systems have had to change to meet patient needs.

This change has already begun in related fields. In cancer treatment, a multimodal approach, including surgery, chemotherapy, radiation, nutrition, and mental health care, has become the standard treatment (DeVita,
Hellman, & Rosenberg, 1989). The emerging field of integrated mental illness and chemical abuse (MICA) treatment emphasizes the importance of using different perspectives and skills simultaneously to treat substance-abusing mentally ill individuals. The MICA approach highlights the need for common training and for appreciation of others' perspectives in managing overlapping treatment problems (Batki, Sorensen, Faltz, & Madover, 1988; Dilley, Shelp, & Batki, 1986; Evans & Sullivan, 1990; Hazelden Foundation, 1993; Minkoff, 1991). In the area of HIV mental health care, Winiarski (1993) described integrated mental health and primary care at community medical clinics.

In addition, national health policy documents such as Healthy People 2000 (U.S. Dept. of Health and Human Services, 1991) and the Latinas Partners for Health Partnership Plan (HDI Projects, 1995, 59–60) provide an agenda for change, recommending increased integration of primary medical care and mental health services.

Our Clinical Practice

How have we begun to unravel our patients' Gordian knots? At St. Joseph's Hospital and Medical Center, in Paterson, New Jersey, our tool is a program that integrates mental health services with HIV-related medical care, both in outpatient clinics and on inpatient units.

The concept of a multidisciplinary, integrated approach to care arose from a philosophy of understanding and meeting the needs of the residents of our community.

In Passaic County, HIV is primarily a family disease, with the most common transmission route being drug use or sexual contact with a drug-using partner. "The virus," as it is known on the streets, has touched families from all ethnic and cultural groups represented in the community, often with three generations affected. Our clients range from newborns to elderly grandparents who are now full-time caretakers of orphaned children. They include prostitutes, hard-core drug users, and prisoners, as well as working single parents with infected partners who are raising their children alone, gay and lesbian individuals who are frequently poor and substance-abusing, and suburban businessmen and their partners. The majority of the individuals on the clinic's active caseload are low-income African Americans or Latinos with few resources besides their families to help them to cope with their many and interrelated problems.

Our project to integrate care was funded in 1991 and again in 1994 by
the Special Projects of National Significance program, created as part of Title II of the Ryan White C.A.R.E. Act. The project's mental health team comprises a coordinator, four social workers, a psychiatrist, and a psychologist, all of whom work along with the doctors, nurses, case managers, and other staff of St. Joseph's Comprehensive Care Center for HIV.

The center provides primary medical care and other ancillary services to people diagnosed with HIV and their families. Its current caseload is more than 1,000 clients from throughout Passaic County, New Jersey. Its offices are in the heart of the community, a block from City Hall. Pediatric and inpatient services are provided on the hospital campus nearby. Our project's mental health staff often work with patients in hospital rooms, medical clinic waiting rooms, the pediatric HIV clinic, the parole office, and drug treatment centers, as well as in their own offices, which are adjacent to the Comprehensive Care Center.

What is a multidisciplinary, integrated approach? Integrated care, as we define it, has the following four characteristics:

1. Professionals from many disciplines, including primary medical care, mental health, and other disciplines, must be located in close proximity, preferably in the same clinic.

2. These professionals must move beyond referrals and parallel treatment to sharing expertise and information about patients.

3. Treatment planning and ongoing clinical decision making must continuously incorporate understandings of a person's situation, needs, and experience that come from the insights and the expertise of each discipline.

4. Treatment must be responsive to events in patients' lives as they occur by being flexible in time, frequency, duration, modality, and place.

Integration of care, continuous throughout treatment, bridges gaps between essential services and addresses problems as people experience them. The case of Sherry is an example of how integrated care works.

Sherry is a thirty-two-year-old mother of four with a seventeen-year history of severe sexual abuse, heroin and cocaine use, and prostitution. After completing inpatient drug treatment, she was found to be HIV-positive. Faced with the full intensity of her problems without the help of drugs, she needed to negotiate medical care, ongoing drug treatment, and mental health services. Emotionally overwhelmed and unable to engage in either parallel or serial treatment by different disciplines, she needed a different model of treatment.
**Integrated Engagement**

In an integrated program, inpatient stays, medical visits, substance abuse treatment, and mental health visits are all used as opportunities for outreach and engagement for other needed services. Mental health staff members make rounds on inpatient units and do outreach in medical clinic waiting rooms and drug treatment programs, getting to know patients and staff and offering their services in an informal manner. Failed intake appointments are seen not as refusals of service but as challenges for more creative outreach efforts. Engagement is seen as a process that may take some time, as it did in Sherry’s case.

Upon discharge from rehabilitation, Sherry asked for help to cope with her HIV diagnosis, her fears of death, and her deep desire to reconnect to her four daughters in a meaningful way before her death. But when she went to a community mental health program for recovering addicts, she was noncompliant and was discharged from the program. At a medical visit at St. Joseph’s, Sherry requested mental health services but failed to keep her appointment. To help her overcome her barriers to accepting treatment, one of the program’s mental health therapists met Sherry with her primary medical care provider, whom she trusted. For several weeks she was seen in therapy in a medical office, where she felt safe and secure, while waiting for her medical appointment. Only after a trusting relationship was established was she seen in the therapist’s office nearby.

Other clients have somewhat different experiences in accessing care. Fred met his therapist in the infectious disease clinic waiting room, and Tiffany, a young mother, began to receive mental health services when she brought her child, Joshua, to the pediatric outpatient clinic for treatment. Ana met her therapist in a methadone maintenance program, while Max was first seen through outreach by a mental health provider in the parole office. His engagement with mental health services reduced his anxiety enough so that he was able to access medical care.

**Integrated Assessment and Treatment Planning**

Although all multidisciplinary treatment planning includes information from both medical and mental health perspectives, an integrated model uses more in-depth and varied information. Mental health staff are able to plan therapeutic interventions better when they understand the emotional impact of disease progression and medication. Similarly, medical staff benefit from knowledge of the patient’s strengths, abilities to cope,
and emotional responses to the progression of the disease and other concerns.

A commitment to work together from all care providers is fundamental. In an integrated model, treatment planning is ongoing. This is particularly important with a disease such as HIV/AIDS, which is characterized by rapid changes in physical and psychological manifestations. Regularly scheduled patient-care planning rounds on both inpatient and outpatient units, including mental health, medical, nursing and social work case management staff, provide a coordinating mechanism.

In Sherry's case, multidisciplinary rounds helped medical staff to understand her repeated psychiatric admissions and her problems keeping medical clinic appointments as resulting from fear, overwhelming problems, and limited coping abilities. Mental health staff began to understand the reality of rapidly decreasing T-helper (CD4) counts and laboratory results indicating serious underlying medical problems. This information helped each discipline plan more appropriate treatment.

**Integrated Treatment**

Individual, couple, family, and group psychotherapy sessions are the building blocks of integrated care, just as they are of traditional care. In an integrated model, however, they may occur in a medical clinic office, in a hospital room, or on the telephone when clients are not strong enough to come to the therapist. Sessions may last for only fifteen minutes or for two hours, according to the client's need and tolerance. Rather than attending weekly, clients may come for therapy several times in one week during periods of crisis and then "check in" only every few weeks at other times. More time is spent in crisis intervention and psychiatric case management activities, such as accompanying a client to court or helping a demented client be admitted to the hospital, than is common in traditional models.

Because the psychiatrist is in the same location as the primary medical providers, they consult and share information quickly and easily while the patient is being seen. Also, we have found that a psychiatric medication record in the medical chart, providing a quickly accessible summary of dosage, frequency, and number prescribed, is a useful communication tool, especially for substance-abusing clients.

Throughout treatment, significant time is spent in consultation between mental health and primary medical care staff on the patient's
progress and evolving needs and on assessment of the effectiveness of treatment. Multidisciplinary rounds provide structured opportunities for consultation, but consultation occurs between rounds as well, particularly during medical or mental health crises. Consistent with the integrated care concept, continuity of care is provided by having the same therapist and psychiatrist follow clients throughout their course of illness, on both an outpatient and an inpatient basis. Telephone contacts, letters, and home visits help maintain the project philosophy and keep people engaged in treatment.

Sherry’s treatment included individual therapy either at the mental health clinic offices or at home by telephone when she was unable to get to the clinic, as well as a few crisis contacts. For a time, she was a regular attendee at a weekly drop-in therapy group for people diagnosed with HIV. Her medications were monitored by the psychiatrist. Her therapist worked closely with her primary care physician and nurse, including them in discussion of her concerns about her illness, especially when her anxiety was high or when she had ambiguous physical symptoms.

Integration of Children and Adolescents

In addition to traditional services, mental health staff provide infected children and adolescents with more active interventions such as accompanying them to medical appointments, helping them to manage injections, or preparing them for hospital admissions through orientation visits. Children are seen at the pediatric outpatient clinic, on the inpatient unit, and in the mental health offices throughout the course of illness. As in traditional services, their parents are brought into mental health treatment whenever possible. In integrated care, special efforts are made to engage mothers and fathers in medical treatment as well.

Uninfected children and adolescents with infected parents are seen for individual and group therapy as early as possible before the parent’s death. Hospital visits to sick parents provide important opportunities to facilitate parent-child communication to help children work through fears and conflicts related to their parents’ illnesses.

Corey, Sherry’s seven-year-old HIV-infected daughter, was removed from the home by protective services workers due to Sherry’s substance abuse. The therapist helped Corey to manage her fears about needles and medications while addressing the pain of separation from her mother. From other families, Sacha and Dwight, both nine, worked through their
grief for their parents in a weekly therapeutic play group, and fifteen-year-old Alysha visited her critically ill mother in the hospital with her therapist to deal with her questions and fears.

Integration with Substance Abuse Treatment

As we saw the effectiveness of the integrated model for people with multiple diagnoses, the concept of integrated care grew to include drug treatment. At first, efforts were made to communicate with drug treatment professionals from other agencies on a case-by-case basis. Sherry’s therapist, for example, reinforced her participation in Narcotics Anonymous, which had been part of her discharge plan, and coordinated her care with her NA program sponsor. As the program evolved, more formal referral and case management systems between mental health and area substance abuse treatment agencies developed. Ultimately, the success of this effort led to hospital-based mental health therapists providing services on-site at substance abuse treatment agencies.

Barriers to Integrated Care

Any new program introduced into an existing organization is likely to encounter barriers. Problems are even more likely with a program that requires different disciplines and departments to work closely together for the first time. Potential barriers include the following:

- Especially in an area such as HIV care, staff may develop tightly knit teams “in the trenches.” Staff members from the new program being integrated may need time to establish their credibility and their devotion to the client population. As in the beloved TV series *M.A.S.H.*, new staff are often accepted best when they produce under fire.
- Basic philosophical differences among medical, mental health and drug treatment professionals complicate communication. Integrated care introduces a new way of thinking about treatment, not just an easier way to make referrals or a different location of offices. Staff need modeling, practice, and time to understand that the new program entails assessing, evaluating, planning, and delivering treatment from varying perspectives.
- More interdisciplinary discussion means more rounds, staff meet-
ings, and time spent explaining, negotiating, and incorporating changes. This need for extensive communication, as well as the need for outreach efforts to engage clients, results in a higher percentage of unbillable time than is typical in traditional programs. Our experience with the program has shown, however, that the model may result in cost savings. It has been effective in decreasing psychiatric emergency room visits among heavy users of such services and in engaging hard-to-reach clients, especially substance abusers, who had not been engaged by traditional programs. Given the growth of managed-care approaches, cost/benefit analyses of the advantages of nontraditional activities in reaching vulnerable populations will be essential to justifying this approach.

Recommendations for Future Practice

Providing mental health services integrated with primary medical care will be an effective way of delivering mental health services in the future, not only for the urban poor with HIV but also as a model for health service delivery in general. The model has implications for four other areas of practice:

1. Other illnesses and other populations. Although integrated care improves access for the traditionally marginalized, many middle-class patients with diseases other than HIV also define themselves as “sick, not crazy” and are emotionally distanced from accessing the mental health services they may need. Any major illness can be emotionally overwhelming. The necessity to choose among an array of complex and technical treatment options increases the stress. If mental health can be defined as one of a spectrum of services available to any patient, more of the people who need such services will receive them.

2. Freestanding mental health services. Integration with primary medical care may be easier for hospital-based mental health clinics than for freestanding facilities, but this model has implications for freestanding clinics as well. In an era of managed care, even free-standing clinics increasingly will have affiliations with medical facilities. These affiliations can become opportunities to integrate services and not just to expand referral networks. Freestanding facilities should consider providing some services onsite at affiliated agencies and allotting some staff time to communicate
with other health care professionals, both through formal consultations and less formal interactions.

3. Mental health and substance abuse. The need to provide medical, mental health, and substance abuse services to people with HIV has already broken down many of the traditional barriers between mental health and substance abuse treatment, and this trend can be expected to continue in the future. The collaborations that have been established, the networks formed, the trust developed will not disappear once a cure has been found for HIV. In many locations beyond Paterson, substance abuse and mental health treatment providers have learned that working together in joint treatment works far better than working separately.

4. Managed care. Finally, as more lives are covered by managed care and as primary-care physicians become treatment gatekeepers, the inclusion of mental health services will be particularly important in several ways. Mental health services can help people cope with catastrophic and chronic illnesses and can reduce the cost of medical care both by identifying those who use mental services when what they need are mental health services (Smith, Rost, & Kashner, 1995) and by helping people make necessary lifestyle changes in diet, exercise, or risky behaviors, such as smoking and unsafe sex, in order to prevent illness. Most of all, integration of mental health services with primary medical care may help primary care providers develop the holistic understanding of the patient on which managed care is based.

Tools for Clinical Practice

After years of experience in promoting integrated care, we have made the following observations:

- Educating medical staff about mental health problems extends their ability to deal with difficult cases more effectively.

  Such education frequently requires considerable time, effort and tact, and includes:

  — Case-by-case demonstrations of effective approaches to deal with difficult or confusing behavior.
  
  — Participation in multidisciplinary rounds, sharing information and discussing cases. Stereotypes of the “difficult drug addict” or the “mental patient” are modified as staff more comprehensively understand patient problems. In addition, discussion of
the impact and the implications of disease progression and treatment helps all staff to think about and manage patients, especially difficult patients, in a less crisis-oriented, more consistent manner.

- **Physical proximity of mental health and health care staff decreases resistance to engaging in mental health care and makes referrals work.**

  Primary medical staff are more likely to make appropriate referrals when they know the people to whom they are referring. Clients are more likely to follow up on referrals when they first meet the new people in a familiar setting.

- **In an integrated program, both mental health and medical visits provide important opportunities for delivering the other service.**

  - Meeting patients informally while they wait for medical or mental health services makes accessing any new service less threatening.
  - Monitoring missed appointments in both clinics helps staff from either clinic to identify and address problems in compliance.
  - Continuing integrated care when clients are hospitalized for disease progression and intensive medical treatment or for psychiatric stabilization helps multidisciplinary staff collaborate to mitigate the patient's stress, prevent regression, and strengthen the ability to cope.

- **Clinical practice in an integrated model with HIV-infected individuals requires a flexible formula.**

  Flexibility can be achieved by:

  - Supplementing individual, family, and group treatment with outreach, brief psychotherapy, home visits, and telephone contacts (Boyd-Franklin & Boland, 1995; Nagler, Adnopoz, & Forsyth, 1995; see also chapters 2 and 3).
  - Taking an active, supportive role with an emphasis on the "here and now" to help people accomplish the social and psychological tasks related to their illness (Christ, 1991; Nagler, Adnopoz, & Forsyth, 1995).
  - Expecting interruptions in treatment. Dealing with chronic, fatal illness and treatment frequently requires periods of "time out" or rest. Substance abuse and recovery remains an ongo-
ing life struggle, often with episodic relapses and hiutures in treatment. These are dealt with by keeping the cases open, maintaining connection with the clients, and accepting them back into treatment, using the same therapist and psychiatrist when they return. Clients who are organically impaired or who have histories of multiple traumas find relating to the same staff less confusing and frustrating.

- **A strong, effective support structure is required for clinical staff to be flexible and available to clients.**

  Both the program coordinator and the secretary/receptionist are crucial in making the program work. The program’s secretary/receptionist serves as the communications hub of the group, keeping track of the whereabouts of the clinical staff as they meet clients in different locations. Pagers for all clinical staff help the secretary to locate them when needed by patients or other staff members.

  The program coordinator must allocate a significant portion of time to communicating with other disciplines as well as help all staff understand the integrated care model. Sufficient time should be allocated also to teaching staff members about integrated care and to supporting them as they deal with the enormous losses associated with HIV.

- **Adjust your expectations for clients’ abstinence from drugs, while maintaining abstinence as a goal.**

  The rigid requirement of abstinence from drugs for mental health treatment in effect denies access to treatment for people with limited life expectancy. Current substance abuse treatment considers relapse part of the treatment process. HIV-infected person may be even more prone to relapse due to the increased social isolation and the constant stresses of this disease (Evans & Sullivan, 1990; Najavits & Weiss, 1994). Looking positively at the time off drugs and supporting the frequency of “clean” episodes can support a person’s strengths and minimize feelings of failure (Orlin & Davis, 1993). This helps develop coping skills, supports limited ego strengths, and gives hope in the face of repeated medical and emotional crises.

- **To be multidisciplinary, you must engage in simultaneous translation into several “foreign languages” much of the time.**
You must spend the time to learn about the perspectives, knowledge bases, jargons, administrative structures, and formal and informal power structures in each of the other disciplines with which you work. Not only must you be able to communicate in the other disciplines' languages and cultures; you must do so as a matter of habit. Negotiating not one but several formal and informal organizational structures when changes need to be made or issues arise is time consuming but essential.

- **Commitment from staff of all disciplines to mutual availability is an essential component of this model.**

Without this commitment, movement from parallel to integrated treatment probably will not occur. Making such a commitment is particularly difficult for professionals, however, because it means giving up some autonomy in practice, which requires trust, education, and a willingness to believe that the new approach can be an improvement. Modeling from leadership helps develop such a commitment, validates the efficacy of the new approach, and allows professionals to give up their autonomy with less anxiety. However, time and patience with oneself and others are needed for commitment to develop.

**Conclusion**

Sherry is now drug free and active in Narcotics Anonymous, where she speaks publicly in its drug and HIV-prevention programs. She is slowly becoming more symptomatic but works closely with her health care team to maintain her health stability as long as possible. Since beginning mental health treatment, Sherry has moved from frequent psychiatric admissions to only one overnight psychiatric admission during the last year. She has reunited with her children in a warm and productive manner. She has coped effectively with multiple deaths of peers from HIV and drug use. While she continues to fear suffering and death, she uses weekly psychotherapy to work through her concerns. Due to her progress in reuniting with her family, her oldest daughter and her mother have helped her put aside her fears of abandonment by assuring her that they will care for her.

In our integrated program, health care professionals were able to understand the overwhelming complexity of Sherry's emotional life. Mental health staff were able to understand the physical and emotional stress
related to her illness and treatment. Together they provided a supportive, integrated structure of care. Sherry was able to focus her energy and strengths to comply with treatment, work through her problems, and feel supported by the many disciplines endeavoring to help her.

REFERENCES

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