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Winiarski, Mark G.

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Case Management: Coordination of Service Delivery for HIV-Infected Individuals

David D. Barney and Betty E. S. Duran

My name is Bobby, and I want to tell you about the Ahalaya Project in Oklahoma City. I was referred to Ahalaya after being diagnosed with HIV in 1992. The day my results came back, the HIV counselor with the health maintenance clinic of the Oklahoma City-County Health Department suggested I meet someone from an American Indian organization that provided HIV/AIDS case management. That same evening I was introduced to Gloria Bellymule, project manager for Ahalaya, and she invited me to visit their offices.

Gloria, my case manager, helped me get services that I needed and may not have received without her help. These included referrals to a homeless shelter when I left my partner, a food pantry for food when I ran out of food stamps, and to Salvation Army for clothing. She also helped me apply for jobs and housing. I needed help with making doctor appointments and getting my medications. Staff provided counseling and helped with other personal stuff like taxes.

When I first learned I was HIV-positive, I felt afraid, alone, and angry, but after attending client support group, I realized I was not alone. I have been a participant in recording a prevention education video on HIV/AIDS and have volunteered as a PWA speaker at conferences and workshops in Oklahoma, New Mexico, and California. I have also been temporarily employed by the project to conduct surveys.

I have participated in sweat lodge and other Indian ceremonies that have helped me in connecting with my American Indian heritage. I believe that all the services and healing ceremonies have helped me build self-esteem and obtain independence. Through
the encouragement and support of staff, I have obtained employment as a teaching assistant at a local university.

Above all, the staff at Ahalaya have been really wonderful to me. They have also been inspirational. I remember a time about a year and a half ago when I was still with my partner and having a difficult time personally, psychologically, and monetarily as a result of this relationship. My caseworker counseled with me, supported me in my decisions, and a member of the staff reached into their own pocket and gave me some money to tide me over. I will never in my life forget the staff for their gestures of caring, love, understanding, and sharing. The Ahalaya Project has been like a second family to me because I know I can always count on them to come through when I need them.

— An Ahalaya client

Case management is an essential component of HIV care because most individuals living with HIV/AIDS have complex needs that exceed those caused by medical or health conditions. Individuals with HIV infection are likely to require additional assistance with emotional, financial, legal, and social problems throughout different stages of their HIV-disease progression (Sonsel, 1989).

**Background Reading**

While there is no one standardized definition of case management, it can usually be agreed that the primary function of case management for HIV-infected persons is to coordinate care (Sierra Health Foundation, 1991). Piette, Thompson, Fleishman, and Mor (1993) have identified two dominant goals for case management:

- Case management links clients with appropriate services to improve the quality of the client’s life.
- Case management should reduce the use of expensive inpatient care, thereby ensuring that more resources are available for a greater number of needy individuals.

The definition and goals, however, should not be taken as literal or exclusive, since a key aspect of effective case management is flexibility
and responsiveness to the particular needs of the client. Indeed, case management practice does vary greatly depending on the types of clients served and the agency providing the case management services.

Even though case management can vary greatly, two dominant types of approaches have been identified in the literature (Piette, Thompson, Fleishman, & Mor, 1993), depending on the organizational setting where the case management is practiced. The first is hospital or medical-based case management, and the second is case management offered by a community-based agency. Each type of setting offers advantages and disadvantages from a client's perspective. Hospital-based caseworkers are usually better able to acquire public entitlement benefits, whereas community-based caseworkers have increased flexibility to work directly with clients in field settings (Indyk, Belville, Lachapelle, Gordon, & Dewart, 1993; Piette, Fleishman, Mor, & Dill, 1990).

The process of case management for HIV-infected individuals has been identified by Piette, Fleishman, Mor, and Thompson (1992) from the experience of twenty HIV-care case management sites. These five steps include:

1. Assessment. During the intake process, clients should receive a comprehensive case assessment that identifies their personal life situations from a holistic perspective, including strengths and weaknesses that the clients can emphasize in their treatment or care plans.

2. Care plan. A written care plan, with goals and objectives related to each client's status, needs to be developed with the client's participation. The plan should identify who will be responsible for each activity stated in the plan.

3. Referral. Referral of clients to social and medical services is a foundation of the actual implementation of the care plan. The core of case management activities usually includes, but is not limited to, coordination of service delivery, counseling, and advocacy functions.

4. Monitoring. Monitoring includes frequent checking to ensure that services are actually being provided to the client and that the case plan is being followed. It is also important to conduct regularly scheduled reassessments of the plan.

5. Advocacy. Throughout case management services, advocacy is necessary to ensure that entitlements are received and services are delivered. The purpose of advocacy is to eliminate barriers that limit access to the needed support services. Caseworkers can be advocates at the client level,
by advocating for the individual needs of a particular client, or at the systems level, by promoting the interests of a group of the agency’s clients.

Our Clinical Work

The Ahalaya Project in Oklahoma City is a case management agency that serves American Indian clients throughout the state of Oklahoma. The staff is, for the most part, American Indian. The director of client services is from Pojoaque Pueblo where she has served as governor of her tribe and as a tribal council member. The project manager and one case manager are Cheyenne, one case manager is Cheyenne/Kiowa, one case manager is Cherokee, and the administrative assistant is Pawnee. Staff are professional social workers, registered nurses, and alcohol and substance abuse counselors. All are committed to working with American Indians and the multiple social issues they are confronted with, especially in the area of HIV prevention and direct care.

When working with American Indians, a culturally unique population, it is essential to determine the cultural barriers that affect clients when they are accessing medical and social services. Community needs and culturally sensitive approaches to offering services also need to be determined. This requires input from clients and community representatives in the development of case management services and in the selection of staff to be employed by the agency. At our agency, the goal, in addition to providing the best case management services possible, has been to determine what constitutes effective case management for American Indian clients.

In the development of culturally relevant services for a specific population of persons, it is important to conduct a thorough review of existing professional literature that may assist the provider in identifying specific cultural differences, values, social and psychological issues, and past response to Western therapies, medical treatments, and social services. The literature reports that due to historical oppression and to their distrust of Western culture, American Indians do not use Western medicine or mental health services and seek assistance through social service programs at lower rates than the general population.

In addition, the literature on Indian spirituality and traditional healing suggests that a blending of Western medicine and Indian traditional healing has increased receptivity to treatment by American Indians receiving psychological and medical care. Tribal ritual and ceremonial practices
provide a code for ethical behavior and a social organization that contribute to a meaning of life. It also provides a means for intervening in individual and social dysfunction. Information from existing literature and the participation of American Indian representatives in the development of culturally relevant services have aided in the development of services that are responsive to American Indians living with HIV.

At the Ahalaya Project, we have started with the traditional model of case management, a model built on the belief that clients' needs are too great to be met by any one agency. Accessing multiple agencies to meet client needs is thought of as a "horizontal" orientation to case management. We have also addressed the reality that American Indians and persons living with HIV are often confronted with multiple problems and personal needs. These clients are dealing with social stigma and discrimination arising from one or more of the following factors: homosexuality, HIV infection, racial and ethnic heritage, poverty, illiteracy, homelessness, and poor mental health. Many of our clients have experienced working with social service systems that have complex eligibility criteria, are perceived as nonsupportive, and treat human beings as numbers or cases. It has therefore become important at Ahalaya to assign a primary caseworker who assumes all responsibility for providing and coordinating services for an individual client. This enables the client to develop a close working relationship with the caseworker, enhances trust and increases client compliance with the mutually agreed-on care plan. The one-on-one working relationship also allows the caseworker to become well informed about the client's life (problems, needs, and personal goals), and the caseworker becomes recognized as the person on whom the client can rely on for services and support. Ultimately, this traditional model of case management means that if the client's needs are not adequately addressed, then only the caseworker can be held accountable, and blame cannot be placed on another agency or person.

At the Ahalaya Project, we created an office environment that strengthened cultural identity, supported confidentiality, and provided clients with a dayroom for personal space and a kitchen for their use. We've also made strong efforts to include clients in community education projects. This effort empowers clients by allowing them to invest in the Ahalaya Project's case management services. This sense of ownership increases clients' self-esteem in a nonjudgmental, supportive environment and leads to the development of client support groups and to increased interaction with persons with similar problems and backgrounds.

An important element in creating this environment has been the prac-
tice of employing staff who are culturally sensitive, professional, and committed to working with our American Indian clients. Because of the safe and relaxed environment created, as well as the close working relationship between clients and staff, Ahalaya staff members are often identified by clients and their families as extended family members. Ethically, this type of relationship is discouraged in professional settings, but when working with American Indians it is important to recognize that interference from outsiders is unacceptable. Establishing an identity with the client as a person from the family or community enhances the case-worker’s ability to recommend services and behavior changes with success.

After starting with the traditional model as our foundation for case management services, we knew that our clients would have unique programming needs because of their cultural heritage as American Indian people. So we added new concepts and components to the case management program. From a design perspective, we built in the opportunity for our caseworkers to do much of their work with clients in the field. This means that our caseworkers have the ability to work beyond their office doors — to be in hospitals, medical offices, public entitlement programs, clients' homes, and places where the client is located and needs the caseworker's support or guidance. This also allows caseworkers to provide education on HIV transmission, disease progression, and care of an HIV-infected person to family and community members; work on issues of family and community reunification (important for clients who have severed family ties due to their sexual orientation or other personal issues), and assist the client in identifying resources and supports within the community.

An important component of the Ahalaya Project is traditional spirituality and healing services. Although our clients come from different tribal backgrounds and have varying degrees of American Indian identity, many of the clients wish to participate in American Indian spirituality and traditional healing. This aspect of the project allows caseworkers to aid clients in learning more about themselves and their tribal backgrounds, sharing their knowledge base with other clients, and actively participating in traditional ceremonies. We have found that this practice increases clients' senses of personal identity, enhances self-esteem, and increases their desire to interact with other clients. It also provides opportunities to teach clients stress management, health care practices, nutrition, and use of natural/herbal medicines.

In American Indian culture, there is a belief that a person is subject to
illness caused by natural and supernatural causes. Through traditional spirituality, clients are able to work out many personal issues that they believe are not related to their physical health. (Under the American Indian belief system, there are three causes for illness, both mental and physical. These are natural illness, such as broken bones and cuts; disease caused by the supernatural, such as curses; and non-Indian disease associated with contact with non-Indian culture. Illnesses also fall into three categories: illness only traditional healers can treat; illness only Western medicine can treat, and illness both methods can treat, comprising the majority of all illness [Baines, 1992].) Through ceremony, clients may seek the support of their ancestors through healing, seeking guidance, or releasing a recently departed into the care of the ancestors and their creator.

Death and dying are significant issues in clients’ lives. These topics are discussed in therapeutic interventions and in client support group discussions. Traditional Indian elders are often invited to teach on the topic of death and dying and to conduct ceremonies for clients and staff. A common ceremony is the spirit-releasing ceremony conducted after the death of a client. This ceremony allows clients and staff to reach closure with the deceased while providing support for each other.

It is important to remember that these supports are important not only for clients but for staff as well. Caseworkers and other staff develop close ties to the agency’s clients. We experience frustration with the lack of available services and the social stigma attached to HIV, stress from work demands, and anxiety from working with clients faced with incurable disease. We suffer exhaustion from long hours worked and feel personal grief over the dying process of our clients. We at Ahalaya therefore also provide a therapeutic group for staff to address these issues and to encourage staff to participate in spiritual and healing ceremonies with or in behalf of clients.

In addition to the more obvious medical needs related to HIV infection, clients also have substantial needs for mental health services. Among our case management clients at the Ahalaya Project, 26 percent have been or are presently receiving mental health treatment. Eighteen percent have a long-term history of mental illness; 19 percent have a history of homelessness; 64 percent have a history of abuse of alcohol or other substances or both. Despite these substantial social barriers and the disadvantaged backgrounds of most of our clients, we have found that our agency’s case management services actually improved their quality of life. By using a
pre- and posttest instrument, we found that the improvement in the quality of life to be statistically significant \((p = .01)\). (For more on evaluation, see chapters 17 and 18.)

Since the development of the traditional model of case management, in which one individual is assigned complete responsibility for a case, a newer model has arisen. This alternative model provides case management services through an HIV-care team. HIV-care teams are usually composed of a combination of staff from social services and medical care programs. A typical team is likely to have a case manager from the social service department, a mental health specialist, a nurse, a physician, and many others. Each team member is responsible for ensuring that the client gets services related to the area of that member’s specialty. HIV-care teams represent a “vertical” approach to brokering services, with almost all services being offered within one agency, rather than multiple agencies. Teams can, however, include staff from several agencies, depending on the structure of the local social and medical service delivery system. In large part, the type of agency that serves the client will determine whether a team approach or an individual caseworker is more appropriate. Larger programs which have medical providers, such as medical clinics and hospitals, can benefit from the team approach. This approach is more difficult to implement in smaller agencies with limited staff or with programs that don’t provide health or medical services.

**Barriers to Case Management**

Case managers may face the following barriers:

- **Large caseloads.** Perhaps the most common problem associated with providing case management services is that of large caseloads. The majority of community-based agencies that provide case management services are funded under Title I or Title II of the Ryan White C.A.R.E. Act. These agencies usually have caseloads that range anywhere from a low of fifty to four hundred clients, an often-unmanageable size, given the high level of neediness of HIV-infected individuals.

  One way to address the problem of high caseloads has been to use case aides, persons with a strong sense of personal commitment to the affected community, to supplement caseworkers’ activities. While this is clearly beneficial to the caseworker, there
are quality-of-care issues to consider; if the coordination between the caseworker (who holds primary responsibility for the client's case) and the case aides is not adequate, then the quality of care provided by case management services will diminish. Additional concern and planning are necessary when using case aides as substitutes for caseworkers. In general, if caseloads are too high, it is necessary to evaluate if enough case activity is actually being provided to properly call it case management.

- **Inappropriate case mix.** Another barrier to providing quality case management services is an inappropriate case mix. By case mix we refer to the range of different types of clients in a caseload. The concern in HIV case management is that individuals in the symptomatic end stages of HIV infection require substantially more caseworker time than do those with early, asymptomatic HIV infection. If by chance a caseworker were to have a majority of clients in the final stages of the disease, then that caseload would need to be reduced. On the other hand, if a caseworker were to have predominately asymptomatic HIV cases, then he or she could be assigned a larger number of clients. The effect of having a caseload made up predominately of AIDS clients, or of having a high caseload, is a caseworker whose activities shift into a "crisis mode" in which the caseworker spends the majority of his or her time responding only to the most critical situations that the most vociferous clients may be encountering. This type of crisis-oriented case management is usually inadequate to qualify conceptually as actual case management, since the caseworker has little time to conduct prevention-oriented activities mostly for HIV-asymptomatic clients. Prevention-oriented activities, such as good nutrition or early response to an infection, are essential to prolonging clients' life expectancies.

- **Inadequate resources.** Social and medical services can often be nearly impossible to locate and access. HIV-infected individuals have substantial needs for a wide variety of social and medical services, including, but not limited to, low-cost housing, medical care, affordable prescriptions, and an income adequate to pay for necessities such as utilities and food when the clients are disabled in the advanced stages of AIDS. Unfortunately, many of the social service and medical service delivery systems are poorly designed and lack adequate resources to respond to all of the
clients’ needs. An experienced caseworker will be able to acquire more benefits for clients; however, it is likely that many client needs will be unfulfilled. Even though it is in some circumstances considered unprofessional, it is not unusual for a caseworker to subsidize a client’s prescription purchases. Caring for the client’s well-being has become one important expression of what case management is about.

• Difficulty in making referrals. The cornerstone of case management activity is the ability to make referrals to other agencies to satisfy client needs. Even though this sounds simple, in reality it can be one of the more difficult and time-consuming activities for the caseworker. A successful referral is one in which contact is made with the secondary agency, the agency agrees that the client meets its criteria for eligibility for services, and the client is actually able to follow through with the intake appointment. After those steps, it is essential that follow-up be completed. This entails contacting either the referred-to agency or the client to ensure that the referral actually happened and that the referral will meet the client’s needs. In general, a successful referral means crossing bureaucratic lines and negotiating a jungle of complicated eligibility rules. As the caseworker becomes more familiar with the social and medical services community, referrals may become easier but only after the caseworker has put in a lot of time in the field.

• Transportation difficulties. Convenient transportation is essential and often difficult to access. For many caseworkers, transportation issues related to getting clients to appointments are critical. Often caseworkers find themselves conducting client interviews while driving the clients to medical or counseling appointments. The transportation issue is one reason that case management services tend to be more effective in urban areas, which usually have public transportation that can be accessed by a majority of clients. When an agency is located in a rural area, however, and many of its clients do not have access to personal or public transportation, then accessing social and medical services becomes nearly impossible. Most agencies located in rural areas struggle to provide case management services. Their budgets and caseloads need to be modified to represent the concerns of increased costs and time required for transportation. At present,
there are few models of case management services that effectively serve rural populations.

Tools for Clinical Practice

Drawing on our project’s experience, we have made these observations:

- **Case management services need to be targeted to a diverse client base.**
  
  Even though HIV-infected individuals share a strong bond based on the common experience of their HIV status, caseworkers must be aware that their caseloads will be very heterogeneous. About 50 to 70 percent of our caseloads are gay men, with the remainder a mix of intravenous drug users, those infected through heterosexual transmission, hemophiliacs, and infants and children. Over time, it is also reasonable to expect that the composition of caseloads will change as the HIV virus targets different groups. Caseworkers need to be flexible in addressing client needs in the context of a particular group’s values. Even within a group, such as gay men, there is much diversity. Caseworkers therefore should not emphasize one population too much in their activities and should be careful not to respond to group stereotypes.

- **Client mental health and medical needs should be monitored regularly.**
  
  Acquiring HIV disease is a major life experience that requires attention to all the details of a client’s life. Clearly, physical, emotional, and spiritual needs should be continuously reassessed to ensure that none of the spheres of a client’s life are overlooked. Practitioners must be sure to consider their clients’ needs in ways that exceed the boundaries of their disciplines.

  In particular, it is essential that the mental health needs of clients not be overshadowed by medical issues. After the first diagnosis of HIV infection, some clients become clinically depressed. This is to be expected, given the associated consequences of being infected with HIV. Medications have been successfully prescribed that help clients with the initial depression. Suicide risk and dangerousness to others need to be assessed and reassessed. Clients’ mental health changes continuously in response to both life situations and advancing stages of HIV progression.

  At the Ahalaya Project, our evaluation efforts have indicated
that the most important mental health-related goal of case management, from our clients’ perspective, is to reduce stress. Clients believe that good case management is a service that reduces stress in their lives. Careful attention should therefore be placed on stress reduction activities.

One area of controversy in HIV case management has been whether caseworkers should be responsible for monitoring the health status of their clients. We recommend to caseworkers that they accept this responsibility, since this is a critical part of a client’s life that cannot be overlooked. (See chapter 1 for related information.)

- **Positive self-esteem must be built into the care plan for successful case management outcomes.**

  It is important to recognize that many clients come from backgrounds that have negatively affected their self-esteem. It therefore becomes crucial for the agency environment, the agency staff, and the primary caseworker to be cognizant of the need to enhance their clients’ self-esteem. The care plan and service delivery should focus on clients’ strengths. In therapy it may be necessary to discuss clients’ deficiencies, but it is important to use the deficiencies as learning tools by discussing them as life experiences that were not productive but that were ultimately beneficial because they allowed the clients to learn from them.

  In developing the care plan, the caseworker begins by assigning the client simple tasks, but over time the client’s responsibilities increase to the point where the client is achieving most of the results independently. The caseworker should provide recognition throughout to the client for all achievements, regardless of their significance. In addition, the client should feel comfortable asking the caseworker for assistance with issues that are perceived as difficult or intimidating. The important point is that development of improved self-esteem leads to positive life changes. Positive self-esteem is necessary before we can effectively ask clients to make radical changes in their health and social behaviors.

- **Clinicians must be sure that their case management programs offer clients the opportunity to interact with others of similar background who are also HIV-infected.**

  Many clients are isolated due to their sexual orientation, poor
health, and other social issues. The agency needs to develop support services that allow clients to meet other persons with similar needs and problems. Client therapeutic groups, talking circles, group discussions, social activities, and community meetings need to be available. Our clients say that through these opportunities their stress and anxiety are reduced, they are made to feel less alone, personal fears are reduced, they come to realize that others share their feelings and concerns, and they learn about other community resources—all while making new friends. Through the sharing of personal life experiences, some clients may come to seek additional therapy to resolve pending life issues. Peer support often results in positive life changes.

- **Permanency planning on behalf of the clients who are parents is an essential activity of case management.**

Caseworkers in future years are likely to find increasing numbers of dependent children in clients' families. This can be mostly attributed to escalating number of HIV-infected women on caseloads. It is critical, however, that caseworkers be aware that men are increasingly becoming the exclusive caretakers for children. When an HIV-infected client has minor children for whom he or she is the sole provider, the caseworker will need to have permanency planning as an important component of the case management services. By permanency planning, we are referring to the creation of a plan whereby the children will have a permanent home available to them after the death of the primary caretaker. In case management programs it is known that this is the service that caseworkers like least to provide, if they did actually provide the service. It is difficult to talk with a mother or father about the care of children after the parent's death. There is no easy way to do this, but it is imperative for the welfare of the children that a well-constructed plan be developed as soon as possible, ideally during the early stages of asymptomatic HIV infection. This will reduce or perhaps prevent custody disputes after the death of the parent. Even if there are not competing divisions of the extended family likely to vie for custody, permanency planning will designate an appropriate family for the children.

In addition to the difficulty of discussing death with a parent, permanency planning includes another difficult task. The caseworker will probably need to contact individuals and family
members and, in the process of discussing the children's needs, reveal the client's HIV status. This comes after the caseworker skillfully negotiates confidentiality concerns, balancing the parent's right to confidentiality against the best interests of the children. As a rule, clients approve the release of HIV status to friends and family members on a "need-to-know basis."

- **Secondary prevention education is another essential part of case managing those individuals who are HIV-infected.**

  HIV prevention is a ongoing activity. It will never be enough just to educate the current young adult and adult populations without considering that younger persons are continuously maturing and entering higher-risk age groups. HIV education is necessary for our clients as well. It is insufficient to assume that once an individual becomes HIV-infected, he or she no longer needs to be educated about the risk of spreading HIV. Once an individual becomes HIV-infected, that person moves from being at risk to being a potential risk to others. Clients need education to help them prevent the spread of HIV to others. One of a caseworker's professional roles is to be an agent of social control. Social institutions will hold workers responsible, in some part, for guaranteeing that their clients have the requisite knowledge to aid them in not infecting others. HIV-infected clients also have the potential to reinfect other HIV-positive individuals with different strains of the virus. (For secondary prevention information, see chapter 8).

- **Death and dying and burnout are all interrelated issues that must be regularly addressed in the practice setting.**

  When working with HIV-infected individuals, caseworkers must be continuously aware of their clients' concern with death and dying. Some clients may feel comfortable about the issue of death, as this is often regarded as a natural process. One event that increases a client's anxiety about death is the death from AIDS of another client. The caseworker and the agency need to be prepared to bring clients together at times when another client dies. Support and therapy should be provided to them as individuals or as a group.

  The process of dying causes a great deal of stress and anxiety for all clients. When diagnosed with a terminal disease, the natural response is, "I will die before my time." Clients are faced with
thinking about how much time they have left, what they want to achieve before they die, and, most important, whether their disease process will involve long periods of illness and hospitalization. Issues of dependency, financial obligations, family, and other concerns continuously confront clients. It is important for caseworkers to aid in the development of supportive forums where individual clients or groups of clients can address these concerns. If cultural or spiritual methods of addressing these issues are available, caseworkers can encourage clients to access these services as well.

It is important to remember also that staff must deal with death and dying and burnout. Staff burnout among caseworkers is very common. The agency must provide support to staff in addressing the issues of client death and dying, as well as providing therapy for staff members. Staff should develop groups to discuss work issues related to stresses and problems encountered in working with terminally ill clients. Flex-time for caseworkers may also be approved by the agency. Supervisors need to encourage staff to take leave on a regular basis and continuing education and training on HIV need to be made available to staff and clients.

REFERENCES

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