



Getting Started: Basic Skills for Effective Social Work with People with HIV and AIDS

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Why Do This? Statement of the Problem/Issues

In the second decade of the AIDS epidemic, social workers in practice in large urban centers expect to encounter clients who either have AIDS themselves or have a loved one or family member living with HIV/AIDS and thus have begun to develop the knowledge and skills necessary to work effectively with these populations. Yet even as the epidemic rages on and shows no indications of abating, there are social workers who believe that there is no need to prepare themselves to work with clients whose lives have been impacted by HIV/AIDS. For workers in small cities away from the coasts or who practice in rural areas, or specialized settings, (e.g. Christian counseling centers or agencies that serve Orthodox Jewish families), all too often the assumption has been, "AIDS is not a problem in this community, so why should I learn about it?"

Current demographics demonstrate that even in rural areas without a well defined gay or drug using sub-culture, cases of AIDS are on the rise. Increasingly, people with AIDS are leaving the large urban centers where they have contracted the illness and are returning home to live out their final days with their families of origin. In *My Own Country* (1994) the author describes his experience providing primary medical care and becoming the local AIDS expert in a remote area of rural Tennessee. He is honest about how his own preconceptions of who his patients were going to be were quickly challenged by the variety of men and women who sought out his services.

AIDS Work Is the Cutting Edge of Contemporary Practice

Ostrow and Wren (1991) state the following:

"Mental health care providers are increasingly instrumental in efforts to control the AIDS

epidemic. AIDS is as much a behavioral as an infectious disease problem. This is evident by the manner of its transmission, its effects on the central nervous system, its stigmatic nature, and its often lethal outcome. Specialists in mental health care and behavioral change are indispensable in controlling the epidemic through education, prevention, treatment, and research. Mental health care givers can help people overcome the biases that impede rational responses to the disease and fears that characterize the AIDS epidemic by providing compassionate care and by suggesting innovative methods of prevention and research."

Serving people with AIDS encompasses the traditional social work role of advocate for an under served client population and poses professional challenges and satisfaction for all workers. If there has not been any in service training on working with people with AIDS for agency or hospital staff, then an excellent starting place is for a social worker to locate a local expert who can be brought in to do an introductory training about AIDS for the staff *even if there have not yet been any clients presenting with HIV or AIDS issues*. If a social agency waits until it is faced with it's first client with HIV or AIDS to become familiar with the practical and psychosocial issues relevant to providing good quality care, it has waited too long and the services to the client will suffer out of ignorance or fear. Therefore, all social workers need to arm themselves with the basic knowledge about assessing risk behavior, local resources and skills about intervening appropriately in order to be prepared to best serve the vulnerable client who will surely not be in any condition to educate the worker, although frequently clients with HIV and AIDS do educate social workers, physicians and other health care professionals

This chapter serves as an introductory overview to direct social work practice with people affected by HIV and AIDS. Mental health and casework issues for both the individual who is infected or ill, as well as his or her loved ones will be discussed. I begin by addressing how to integrate HIV risk assessment and prevention into routine interviews with a variety of clients of all sexual orientations and drug using status. Next the issues involved with helping clients decide whether or not to be tested for HIV and what social workers need to know to be prepared for working with HIV positive clients is covered. I then move into how workers can be helpful to people actually living with AIDS. The chapter concludes with a detailed discussion of counseling end stage AIDS patients, their families and other loved ones as death approaches. While this chapter is intended to be instructive and stand on its own, like all of the other chapters in this book, it can best be complimented by your attending live trainings about HIV and AIDS.

Assessing Clients' Risks of Exposure to HIV

Before the development in 1985 of an accurate test to determine the presence of HIV in blood products, people who received transfusions or clotting factors were at risk of contracting HIV through blood they were given. Currently the vast majority of new HIV infections occur either through sexual exposure or sharing intravenous drug using apparatus. In attempting to assess whether a client is at risk for AIDS, a social worker must ascertain both the client's current sexual practices as well as what they were in past. Simply asking "Are you gay?" is not sufficient. Health care professionals cannot assume that a client who is not openly gay has not engaged in sex with other men. Once a man labels himself as gay, this is a good indication that his identity is largely affiliated with his preference for loving men, having male sexual partners and making choices in his life in order to integrate these desires with a satisfying emotional and social life. Some men who regularly engage in sex with other men, never think of themselves as gay or even as homosexual, and never seek to affiliate with the gay community.

The distinction between men who simply have sex with other men and men who have a gay identity is especially relevant when working with nonwhite and/or non-middle class men. For example, contemporary African-American culture widely condemns homosexuality, and homosexual identification is widely denied,

even as male-male sex is widely practiced. According to a recent survey of 65,000 HIV positive men, blacks are twice as likely as whites to practice bisexuality, and among black drug users, many of whom turn to prostitution to support their habit, the incidence of bisexuality is four times as high as reported in non-African Americans (Cargill, 1995). Some men who actively engage in sex with other men, do not view themselves as homosexual or gay because they are doing the penetrating. For example, a married man with numerous symptoms of progressive HIV infection who had never received a transfusion or blood products, who reported no history of shared needle use or other risk factors for exposure to HIV, and who stated he was definitely not gay, baffled his physician. However, when the man was questioned in an extremely nonjudgmental way by a social worker as to whether he had ever had sex with other men, the client readily stated that he had a long history of sexual activity with men.

In attempting to do a risk assessment for high-risk behavior the social worker needs to ask questions regarding drug taking and sexual practices in an accepting, nonjudgmental, matter of fact gentle way that does not incorporate the use of labels. Springer (1991) suggests that in order to be able to engage chemically dependent individuals in AIDS prevention and treatment social workers need to learn how to talk to drug users honestly and completely about their drug use.

Some examples of these questions are:

- Have you ever used drugs, and if so which ones, and how have you taken them?
- As an adult have you ever had any sexual contact with another man? If the answer is "Yes," then ask "When was the last time?" or "Could you tell me exactly what you did?"

The answers to these questions can provide useful and pertinent information about the client's risk potential. Prior to initiating these discussions, the social worker must offer assurances and guarantees about the confidentiality of the information being elicited. Consistent with social work ethics, workers in all settings must be extra vigilant not to gossip about their clients who may also be their neighbors. In addition, social workers can reduce their discomfort about asking the above questions by routinely incorporating them into initial interviews with all clients.

Examples of How the Issue May Present

Social workers working with people who do not self-identify as gay or bisexual, or who report no history of drug use may assume that their clients are not at risk for becoming infected with HIV. It is true that sexually exclusive monogamy will protect people from HIV infection if both partners are already HIV-negative. However, the research of Kinsey and coworkers (1948) and Hunt (1974) suggests that more than 50 percent of heterosexual couples in the United States have more than one sexual partner during the course of their marriage. Even couples who are currently sexually exclusive are not protected from the consequences of risk behaviors in which they or their partner may have engaged prior to the relationship.

Regardless of sexual orientation, people cannot be absolutely certain about the drug use or sexual history of their sexual partners. Because the time from initial infection until the appearance of first symptoms is usually several years, people may unknowingly transmit or expose themselves to HIV, erroneously believing that they are not at risk because they are currently in a stable, exclusive relationship. In interpreting data from the studies of Kinsey (1948) and Hunt (1974), Hyde (1982) found that only 2 percent of American men are behaviorally exclusively homosexual during their lifetime and that 25 percent are behaviorally bisexual at some point. These data suggest that the majority of men who are or have been homosexually active in the United States may not identify themselves as gay. Many of these men remain in heterosexual marriages,

possibly hiding their homosexuality from their wives. Thus, many women may falsely assume that they are safe from the risk of contracting AIDS.

AIDS Within Heterosexual Marriage

Social workers need to be aware of a variety of cultural or dynamic situations that contribute to the likelihood of heterosexually married individuals presenting as HIV positive or with symptoms or AIDS. Societal homophobia is a powerful influence in why many men, of diverse ethnicities choose to hide their homosexual activity within a heterosexual marriage. A husband's or wife's past or current drug use also places unsuspecting spouses at risk for HIV or AIDS. The following cases illustrate a variety of ways that social workers may encounter this face of AIDS.

A woman client learned in one day that her husband of fifteen years had AIDS, that her marriage had not been a sexually exclusive relationship, and that her husband's relationships outside of the marriage had been with men. The crisis was compounded by the need to decide what to tell their fourteen year old son regarding his father's illness and worries that she herself might have been exposed to HIV.

A social worker runs a group for nondrug using Latina women with AIDS, all of whom were themselves monogamous and yet were infected by their husbands who had either contracted HIV from drug use or sexual liaisons outside of the marriage. Issues of betrayal and rage are paramount for these women along with adjusting to living with a life threatening illness and the stigma of having AIDS within their community.

Social workers on staff at pre-natal clinics daily counsel monogamous heterosexually married pregnant women who discover that they have been infected with HIV by their husbands.

Two days a week a social worker sees clients in his private practice in Borough Park, Brooklyn. All the clients are ultra-orthodox Jewish Hasidic men who have sought out counseling because they identify as gay, and regularly have sex with other men. Each of the men is either already engaged or married to a woman.

AIDS Prevention: Drug Use

Newmeyer (1989) notes that use of alcohol and illegal substances increases a person's vulnerability to HIV in three ways:

- First, a person who shares hypodermic needles or other drug paraphernalia - such as "cookers" (the container in which the drug is dissolved in water) or "cotton" (the material used to strain the drug solution as it is drawn up into the syringe) -- with someone infected with HIV is at risk of becoming infected.
- Second, a person who becomes intoxicated may lose inhibitions against risky practices, e.g., neglecting the use of a condom during a drunken or stoned sexual encounter.
- Third, a number of substances, such as alcohol, cannabis, amphetamines, inhaled nitrates, and cocaine, may suppress one's immune system. Heavy use of an immunosuppressive substance by HIV infected individuals can accelerate the collapse of "helper" T-cell activity.

In describing the "[harm reduction](#)" model of working with drug users, Springer (1991) suggests that placing

abstinence from drugs as the highest treatment priority unless the client is truly committed to achieving abstinence, will only alienate the client or cause him or her to begin a dishonest relationship with the social worker. Thus social workers attempting to engage chemically dependent clients in treatment must not confuse the goals of providing AIDS education and risk reduction with the goals of helping clients stop using drugs. One way of helping accomplish this is by clearly counseling clients as follows:

- If you do not want to contract AIDS, the best way to avoid it is by not using drugs. I can refer you to an agency or program that can help you to stop using drugs.
- If you must use drugs, do not share paraphernalia such as needles or cookers. Remember that people can look healthy and still carry the AIDS virus.
- If you must share paraphernalia, flush the needle, syringe and cooker with bleach, and rinse well with water -- or boil for 15 minutes.
- To reduce the risk of contracting AIDS through sexual contact, use condoms, avoid contact with semen or blood and learn safe sexual practices.

Taking the above approach in sessions with active drug using clients does not condone drug use, but it does acknowledge the reality that people who still actively use drugs are in desperate need of AIDS education services so as not to transmit HIV to drug using or sexual partners or their children.

Sexual Practices

Unfortunately the vast majority of social workers complete their graduate education and even post-graduate training with little or no education in how to talk with clients about sex and sexuality, and no training in how to take a sexual history. Discussing sexual issues can cause discomfort even for the most sophisticated worker. This is especially true if the discussion involves sexual practices that the clinician believes are immoral, distasteful, repugnant, or represent a life style or behavior with which the clinician is totally unfamiliar. The potential for countertransferential blunders is enormous when clients disclose marital infidelities, exotic or nonconformist sexual practices or beliefs.

I believe that it is the moral and ethical responsibility of every clinical social worker to introduce the issue of sexual practices in relation to AIDS prevention with each individual:

- who is already sexually active
- who is contemplating becoming sexually active
- who is not absolutely certain that he or she has been in a sexually exclusive relationship for at least the past ten to fifteen years, or
- who is not absolutely certain that his or her partner has not used drugs intravenously or been the recipient of whole blood or blood products prior to the screening of the blood supply in 1985.

Some salient points to consider are as follows:

- The highest risk of contracting HIV has to do with exposure to blood that is already infected. Thus sharing drug injecting paraphernalia or unprotected sex that results in exposure to blood or semen pose the highest risks.

- Unprotected anal sex is the next highest risk behavior, followed by unprotected vaginal sex.
- There is controversy about whether or not fellatio without a condom is high risk. There is a growing body of evidence that suggests it is at least a potentially risky behavior, though not as high risk as either unprotected anal or vaginal intercourse.

The ambiguity about the risks of unprotected fellatio is very hard for most gay male clients and others to deal with who want definitive answers about what is risky and what is not. Many AIDS educators introduce the concept of a risk continuum from lowest risk (mutual masturbation without any penetration) to highest risk. In discussing the relative risks of various sexual acts with clients social workers must be prepared to have clients get angry at them for not being able to provide definite "do's and don'ts."

HIV Risk Reduction and Social Work Practice with Diverse Clients

Thus social workers who see adolescents, individuals in sexually nonexclusive relationships, newly separated, divorced or widowed adults, and any person contemplating having sex with a gay or bisexual man, current or former IV drug user, or transfusion recipient needs to learn about safer sexual practices. The current epidemics of all sexually transmitted diseases, including but not limited to Hepatitis, Herpes, AIDS, and treatment-resistant [gonorrhea](#) has made it appropriate, and in fact essential for clinical social workers to ask clients effective questions about their sexual practices. Some key questions to ask clients are as follows:

- How did you feel when you first heard that you might have to change your sexual behaviors in order not to contract AIDS or other sexually transmitted diseases?
- How do you feel about the fact that AIDS is sexually transmitted?
- Are you concerned about the possibility of contracting HIV?
- When you think about safer sex, what thoughts and feelings do you have?
- What is your definition of safer sex?
- What are you doing to protect yourself and your sexual partners from AIDS?

Safer Sex Counseling in Practice

Social workers should have understandable concerns about introducing these topics. The issue of whether sexual content becomes experienced as overstimulating or "inappropriately eroticized" must be assessed on a case by case basis. Understandably, many clients do not feel comfortable discussing sexual practices and may feel intruded upon or angered by explorations of these issues. However questions concerning sexual behavior outside of marriage or the client's sexuality may raise profound feelings of relief as well as anger.

Anger may occur because any discussion of AIDS shatters the client's ability to deny that the disease can touch him or her. The anger may also reflect how vulnerable and powerless the client feels in seeking social services, and in addition may be a defense in response to having been treated in insensitive or even humiliating ways in prior interactions with social service agencies or workers. If the client's expressions of anger are encouraged, explored and not judged by the worker, a climate of increased trust and safety often

develops between the client and social worker that allows further discussions of highly charged issues. Once clients realize that the social worker welcomes and encourages expressions of all feelings, including negative ones about him or her, clients often express relief that they have a venue for discussing such personal and highly charged issues safely.

It is natural and appropriate for a client to test a worker's responses by gauging how he or she responds when attacked or criticized. Not infrequently I have had clients tell me that they would never have felt safe enough to open up and share vulnerable personal issues with me if I hadn't previously handled their expressed anger or disappointment in a manner that the client was comfortable with.

HIV Testing

The social worker needs to know where anonymous and confidential [HIV testing](#) is available in his or her community in order to make a referral when appropriate. One of the most commonly endorsed protections against HIV-related discrimination is the use of anonymous testing (Marks & Goldblum, 1989). Since even in the second decade of AIDS there is considerable stigma attached to a diagnosis of being HIV positive, the client needs and deserves assurances of the confidentiality of his or her test results. It is also useful to have developed a relationship with a specific individual at the test site to whom you can refer a client with confidence. It is also an excellent idea to know about any existing AIDS service organization and other local HIV/AIDS resources in the community, and which physicians, hospitals and medical centers are most experienced in treating people with HIV/AIDS. Social workers should also educate themselves about the stages of the illness and how its progression may present.

This is especially important in regard to the neuropsychiatric manifestations of the illness, since bizarre or noncooperative responses from clients in the advanced stages of AIDS may be misinterpreted as resistance or hostility as opposed to a symptom of organicity related to the disease. If one is going to be working with clients who have HIV or AIDS it is essential to have a close working relationship with a psychiatrist/psychopharmacologist who is experienced in diagnosing and treating AIDS related [dementia](#).

There are a number of situations when it is clear that a social worker needs to raise the issue of a client's being tested for HIV:

- The client mentions that he or she has recently had or feared he/she has had a sexually transmitted disease.
- A client shares that he or she has discovered that his/her husband/wife/partner has been sexually unfaithful.
- A client has been sexually assaulted or raped.
- A client's partner or spouse is hemophiliac or has received a transfusion prior to the screening of the blood supply in 1985.
- A client reports high risk sexual or drug taking activities like sharing paraphernalia.

It is urgent for the worker to remember that no matter how appropriate it may be that the client be tested for HIV, the final decision about whether or not to be tested must always be the client's. Raising the issue of HIV testing will understandably raise the client's anxiety. Even when the client raises the issue of being tested the worker has to spend time exploring salient issues which include why he or she has decided to be tested at this

time. If the client has not raised the issue of being tested for HIV it is crucial that you inquire how he or she feels about you having raised the issue. In this situation the worker must prepare him/herself for a variety of possible reactions by the client. Many clients react with shock and anger as this suggestion confronts any denial they might still have about possibly being at risk.

Counseling Before and After the HIV Test

Each individual planning to take the HIV test needs to receive pre and post test counseling regardless of whether he/she tests negative or positive. After introducing the topic of being tested for HIV, but prior to actually taking the test, all clients need to explore the following issues:

- How do they feel they will handle learning that they are HIV positive or HIV negative?
- How will whatever the results are change their life?
- Who in their life do they want to share this information with?
- How do they feel a positive test result will impact these relationships?

The period of time while one is waiting for test results is almost always one of heightened anxiety, that often includes somatic symptoms and sleeplessness. If a client is newly in recovery from alcohol or drug abuse, in the midst of other interpersonal or intrapsychic crises, it is generally inadvisable to counsel him or her to take the test at that time. Positive test results can be emotionally devastating sometimes resulting in a psychiatric decompensation, or relapse into active use of alcohol or drugs. If a physician feels there are urgent medical reasons indicating HIV testing, then counseling needs to address this and support the medical advice. For individuals who are newly in recovery from chemical dependency, and for whom there is no medical urgency, but only a desire to learn their HIV status, it is advisable they wait until they have at least a year's sobriety to take the HIV test. Post test counseling must include information on safer sex no matter what the results are, and referrals to medical and mental health services if the client tests positive.

Once a client has learned that he or she has been exposed to HIV the social worker has a number of crucial tasks in order to help him/her adjust to living with a life threatening illness. First and foremost, the worker needs to become extremely educated about HIV disease and AIDS. The worker should establish a relationship with a knowledgeable medical professional who can explain various symptoms, treatments and options to the worker so that the client is not spending his or her time educating the worker about medical issues of the illness. Although AIDS is almost always a terminal illness, it is most often premature for clients to begin preparing for death upon learning that they have just tested positive. Clients need to hear that there is usually a period that increasingly lasts up to ten or more years where people remain asymptomatic and are only HIV positive. (People have full blown AIDS when their CD-4 Cells fall below the 200 mark or they come down with one of the AIDS related [opportunistic infections](#).) Only when other serological tests indicate that the immune system is severely damaged or the client is seriously ill with one of the major AIDS related opportunistic infections may the client simultaneously be learning that he or she has been exposed to HIV and is at risk of dying from a serious AIDS related complication.

Research has demonstrated that women with full blown AIDS are dying quicker than men with AIDS (Kolata, 1987). One reason for this is that inner city people do not generally have a primary care physician, and usually do not go to clinics or doctors for regular or preventative visits. The poor, women, children and addicts, are more apt to use the hospital emergency room for primary medical care, arriving there in run down conditions with severe HIV symptoms or in advanced stages of one of the opportunistic infections associated

with a diagnosis of "full blown" AIDS. With this in mind all social workers with socially disadvantaged clients must use every opportunity to teach these individuals the concept of primary medical care, and urge them to seek regular contact with physicians for themselves and their children. In addition, upon hearing of instances where clinics or physicians have not responded with appropriate sensitivity or urgency the social worker should immediately use his or her status and professional expertise to advocate with the health care setting on the client's behalf.

Ethical, Legal Issues and Confidentiality Related to HIV Antibody Status

Social workers may find themselves in a situation where there is a conflict between loyalty to one's client regarding confidentiality and other ethical concerns.

Case Example

A heterosexually married man sought counseling following learning that a regular male sexual partner had been hospitalized for an AIDS related condition. These men had never practiced safer sex and my client was in a panic that he might be infected and that he might have infected his wife, with whom he was still sexually active. After testing positive for HIV antibodies, he was unwilling to share this information with his wife. I was insistent that he let her know what the situation was, especially since she needed to be tested to ascertain what her health status was. After refusing to tell his wife that he was HIV positive for two months, I gave him the following ultimatum. If he didn't tell his wife within one month and she accompany him into sessions so I could be certain that he had indeed told her about his HIV status and her possible risk, I would call her myself and tell her. I made this decision after consulting with my attorney. Based on an interpretation of the Tarasof ruling in California, she felt that she could defend my potential breach of client therapist confidentiality since there was a potentially life threatening situation involving the wife. Eventually he reluctantly agreed to tell her that he had been tested for HIV after having visited a female prostitute on a business trip and discovered that he had been exposed to HIV.

This case illustrates several points regarding legal, ethical and clinical questions of HIV testing in social work practice. Except in cases of suspected or observed child abuse, the confidentiality of a client's discussions with a social worker is an important foundation of the professional relationship. In the above cited case I faced an ethical dilemma not encountered in my previous twenty years of practice. Since this client was in a relationship with a partner who was unsuspecting of the fact that she might have been placed in a life threatening situation, I felt that his wife's need to be informed about her potential health risk outweighed his need for self-protection. Since my client was not reporting any physical symptoms of HIV disease there did not appear to be a medical immediacy for his knowing his antibody status. Had he been single I would not have pushed him to have been tested as quickly even though there was a good chance he had been infected. Ordinarily counseling would have focused on eliciting his feelings regarding learning that his partner was ill, his own fears and information on how to protect himself and all future sexual partners from spreading the virus.

Universality of the Issues Affecting People Living with HIV/AIDS

It is virtually impossible not to be personally affected by working professionally with people who are seriously ill and dying. When social workers become educated about the relevant issues of people living with HIV and AIDS, the worker becomes better prepared to help any client face a life catastrophe. As Gaies and Knox (1991) point out, "By confronting with dying clients the fragility of life and the value of each day,

social workers begin to confront the vulnerability of their own lives and to acquire a deeper appreciation of living." Even deeply religious people question why bad things happen to them or to the people they love and can greatly benefit from the intervention of a skilled social worker who can help them work through all the accompanying issues and feelings. An additional benefit for the worker of doing this work is that it demystifies death and dying. Asking a client questions about why he or she is making the choice to begin or discontinue a particular treatment and what the ramifications are of those choices helps him or her to look at what he or she values about their life. Working with people who have life threatening illnesses or who are dying and their loved ones, and engaging in conversations about sexuality, spirituality, dying and death, which are all inherent in AIDS work, are invaluable clinical skills that are relevant to all aspects of social work practice with any client population.

Facts the Social Worker Needs to Know Before Proceeding

Living with HIV/AIDS Versus Dying from AIDS

When a social worker first encounters a person with HIV/AIDS or a member of their family or support system, one of the worker's tasks is to help the client balance a realistic sense of hope with practical issues inherent in learning to live with HIV and AIDS. There are increasing numbers of people who have been labeled "non-progressors" because they have a documented exposure to HIV for ten or more years and have remained completely asymptomatic, leading healthy, productive and full lives despite being infected with HIV for over a decade. There are also "long term survivors" who are individuals who have had an AIDS related opportunistic infection and have recovered from the acute phase of illness and have remained reasonably healthy for at least three years following diagnosis with a serious AIDS related complication.

Therefore it is often useful to share this information with newly diagnosed patients and their loved ones in order to help them internalize some hope in adjusting to an HIV or AIDS diagnosis. Hearing from a professional that the diagnosis is most often not an immediate death sentence is a very empowering experience. It is usually beneficial to articulate for the client that he or she or their loved one is currently living with HIV or AIDS, as opposed to dying from AIDS. Much of the practical concrete as well as clinical work will be helping the client adjust emotionally and practically to the state of living with this condition. Nonclinical social workers need to understand this reality and reflect it back to clients. The belief system that, "I'm going to die very soon," should be challenged when offered as a rationalization for acting self-destructively, e.g. like resuming drug or alcohol use or not following up on referrals that will help improve the quality of a client's life.

Supportive Denial

With this in mind it is also useful for the worker to understand the concept of "supportive denial" in helping clients manage living with this condition. Supportive denial means that the client will not keep an awareness of his or her condition in the forefront of his or her thoughts at all times. This is easier if people are not seriously ill, and are in the early phase of their being infected, prior to becoming increasingly symptomatic and debilitated. Denial itself is neither bad nor good. If the client's denial is so pervasive and intense that it impairs the individual's reality testing then the worker needs to challenge it. An example of maladaptive and inappropriate denial is a client in the early phase of HIV illness who refuses to undergo a basic treatment for a treatable opportunistic infection stating either that nothing is seriously wrong or "what's the use since I'm just going to die anyway?"

Another maladaptive example of denial is when an individual denies that he or she is, in fact, at risk for

contracting or transmitting HIV and therefore refuses to change either sexual or drug taking behaviors in order to protect themselves or others. Denial must be assessed regarding how functional it is. If the denial contributes to an adaptive mode of living with the illness then the worker should not challenge it. One way that supportive denial manifests itself is when a client does regularly see his or her physician, has begun long term planning for the illness, but does not necessarily feel any need to discuss AIDS during sessions with the social worker.

Casework with People with AIDS

Social workers employed in social service, child care, or public assistance agencies, drug treatment facilities or hospitals will all face the daunting reality of trying to help economically disadvantaged individuals or families with AIDS obtain or maintain a variety of benefits and entitlements. The work will be even more difficult in areas where extensive concrete and social services for people with AIDS do not already exist. The social worker may find him or herself having to wrestle with already overwhelmed social service agencies faced with dwindling resources. As Walker (1995) notes, "effective service delivery to infected persons requires the creation of productive partnerships between health care and social service professionals as well as families and community groups."

Social workers must learn how to help families negotiate with care providers so they receive accurate information about medical care, treatment options, [nutrition](#) as well as social services. Walker (1995) goes on to point out, social workers employed in service organizations may regard families with AIDS as requiring an inordinate amount of services, and the worker is at risk of becoming dismayed by what they perceive to be the lack of change on the part of the family despite intensive efforts to help them. As a result, social workers - like the families themselves- feel overwhelmed by the myriad problems presented by the families, and may regard these clients as burdensome and unrewarding. The social worker's frustration is further exacerbated when they try, often futilely, to negotiate for the families' welfare, disability, and housing benefits through complex mazes of bureaucracy.

Preparing for Serious Illness

As people develop symptoms of more advanced AIDS they increasingly lose control over their bodies and lives. One task for the social worker is to help people living with HIV and AIDS recognize what they can control. One of the most important areas is being partners in their health care with the physicians, determining which treatments they want to begin or discontinue. As Rabkin et al (1994) point out:

"For many clients, the concept of developing relationships with medical providers and becoming an active member of the medical team is a foreign one. This is especially true for poor people who typically receive care at emergency rooms and clinics where frequent staff rotations and institutional insensitivity is common. Social workers can teach clients how to assert themselves more effectively without being considered abrasive. Role playing is a useful technique for helping clients develop these skills." (p.17)

Clients living with HIV require help in planning for hospitalizations and debilitating illnesses. AIDS related illnesses can have an astonishingly sudden onset. Often clients and their families or support networks are ill prepared to cope with decisions that could have been discussed in depth prior to the onset of a medical emergency. It is best to raise the difficult and painful issues listed below long before there is any apparent need for them. When the client is well he or she is more likely to have the necessary energy for planning these difficult realities. The worker needs to question clients unwillingness to discuss concrete plans or desires for a living will or treatment options long before there is an acute medical emergency. Emphasize to

the clients that by addressing these issues now they can insure that they will have a measure of control over what happens to them.

It is essential that social workers overcome their own discomfort about discussing preparing for the end of life in order to help clients and their families and loved ones prepare for this eventuality. It is useful to raise with all clients, but especially those with a life threatening illness, the issues of having prepared a will, medical proxy and living will. The worker can introduce these issues by stating that although it is clearly much too early to begin to think about some of the difficult realities that accompany having a serious illness, the worker feels that it is in the best interests of the client that these sensitive issues begin to be addressed now. This is certainly true if the client is a single parent and hasn't made any provisions for who will care for their children, if they become too ill to actively parent or who will have custody of the children following his or her death.

Crucial Points

- The client needs to know which hospital he or she wants to be taken to in the event of an emergency.
- If the client lives alone or with small children, they need to discuss who will be contacted, even in the middle of the night, to help them get to the hospital and/or to care for children or pets during the crisis.
- The client needs to maintain a current and complete list of all prescribed medications and dosages that can be brought to the hospital during an emergency admission.
- The client needs to discuss advance medical directives that include how aggressively they wish to be kept alive if there is not any reasonable hope for recovery or for a good quality of life. A living will needs to be made out. These directives need to be written down and given to the physician and brought to the hospital to be placed in the chart at the start of each hospitalization.
- The client needs to designate a health care proxy (a family member or close friend) and ask this person if they feel that they will be able to insure that the client's wishes will be followed *even if those wishes are contrary to what the proxy feels is best*.
- The client needs to be asked, "What do you want done in the eventuality that your heart stops beating?" If a client does not wish to be resuscitated then a "do not resuscitate" (DNR) order needs to be written and placed in his or her chart.
- The client needs to be reminded that they can always revise these instructions if any of their feelings change over the course of their illness.

One of the most important functions of the social worker will be as liaison between the client and his or her family; between the client and physician or other health care providers or home care agency; and between the client and social service agencies. Families and other loved ones are often in greater denial than the client and may benefit greatly from speaking with a social worker.

End of Life Issues

"Few people who are not profoundly depressed speak about being ready to die or welcoming it, except if they are in the advanced stage of a terminal illness. People with AIDS who have become extremely debilitated after going through extensive treatments often speak of being ready to die since they no longer have a meaningful quality of life." (Rabkin et al, 1994)

It is imperative for the worker not to judge these feelings and to elicit how the client feels about approaching the end of his or her life. While directly discussing these issues initially makes clients uncomfortable, it is my experience that clients welcome the worker's raising questions about death, dying and end of life practicalities. One useful way to introduce the topic is by asking what the client believes happens after death, and are those beliefs comforting? Also, exploring a client's feelings or thoughts about the religion in which they were born and raised can be useful in helping discover sources of strengths or of old wounds that might need to have opportunity to heal. I have found that clients are almost always grateful to have the opportunity to speak to a sympathetic clergy person who will not be judgmental about their having AIDS or how they may have contracted it. A list of such clergy is an important and useful resource for all workers to cultivate, so that one can be called upon to visit with a client who is dying and who feels the need for religious reconciliation.

Funerals and Memorial Services

One way of empowering a dying client is by urging them to discuss what they wish done with their bodies after they have died? Do they want to be cremated or buried? Have they written this down? It can be one very comforting option for some people to plan their funeral or memorial service, specify who they wish to speak, what music or prayers should be recited, and where the service should take place. On the other hand, confronting these details may be too stressful for some individuals who can't face what making those plans means in terms of accepting their health status. But if the client has been able to discuss these issues during counseling, the next step is to urge him or her to talk over these details with family and loved ones. If the family or loved ones refuse to discuss these issues with the client then it would be useful for the worker to urge the significant others to come in for some sessions to help them work through their feelings of denial, sadness and discomfort.

These family sessions can help significant others see that once they are clear about the wishes of their loved one, it will make it that much easier for them to carry out his or her wishes after he or she has passed away. It is a useful intervention to restructure the reality from one of morbid preoccupation with the unpleasant inevitability to allowing the person who is ill to take control over the few areas of his or her life that are still controllable. It is also useful to explain to the loved ones that it is an expression of how much the ill person loves them that he or she doesn't want them to have to guess what should be done during the extremely stressful period following their death. It is one way the person who is dying is still able to take care of his or her loved ones.

Pain Management

Rabkin et al (1994) note that most people fear that they will be in excruciating pain as they near death from a terminal illness. Clients need to be assured that they will not suffer. Most major hospitals have physicians who are pain management specialists who can consult with the patient about helping him or her remain comfortable at this phase of the illness. "Some people prefer to be unconscious, others wish to be alert, but sedated and pain free." (Rabkin et al, 1994) People need to be taught how to explicitly describe how much pain they are experiencing in order to effectively communicate this to the physician. Pain can be effectively controlled even if the client decides to die at home. In addition, social workers can help clients who experience pain by teaching them the techniques of self-hypnosis and visualization.

Weiss (1995) states that:

"Actively chemically dependent patients with AIDS usually require generous amounts of medication while in the hospital. Medical and nursing staff often withhold the very medication

these patients need, making them even more irritable and difficult to manage. Making patients comfortable with adequate opiates or sedatives helps them feel they are being heard, enhances their trust, and improves the working relationship between the chemically dependent patient and staff members."

Hospital social workers need to be alert to the above mentioned dynamic and be prepared to advocate for chemically dependent patients who are not being adequately medicated. Conversely, some patients who are in recovery have unrealistic expectations regarding using any drug that they once may have taken illicitly. Social workers need to remind people that they did not get sober to suffer and that taking prescribed medication to alleviate pain is not the same as abusing drugs.

Choices in Dying

One major issue for dying people is that they are at a point where their ability to control what happens to them has been greatly diminished. Clients at the end of their lives can be empowered by social workers engaging them in a discussion about where they want to die. Many clients may not realize that whether to die at home, in the hospital or in a hospice is a decision that they and their loved ones can and should consciously make together in consultation with the physician. It can be enormously helpful if the social worker explains hospice care. Suggesting that an intake worker from hospice visit the client to describe the program in detail is one useful intervention. These discussions are best held in at least two different sessions. The first is with the client alone to explore all of his or her feelings about this emotionally laden issue. Next the discussion needs to be continued with the people, if there are any, who will help care for the client, in order to explore all the emotional as well as logistical and practical considerations.

As Rabkin et al (1994) note, "It can often be difficult for all concerned to acknowledge that "enough is enough." It is the role of the social worker to explore with the client his or her feelings about whether or not to cease treatments or to continue fighting for extra time. It is not the worker's role to give permission for one choice or another, though the client may be asking the worker either directly or obliquely for his or her opinion about what course of action seems to be best. Dying can be a quality time both for the terminally ill person as well as those who love him or her. As Hines and Peura (1995) explain:

"...at a certain point, we must all let go of living well and begin to consider what it means to be dying well. This can become a very attractive concept for the client, the significant others and the worker. Many of us associate the dying process with all the worst things, from pain to mental deterioration, But through counseling, a skilled worker can help the client explore what it would mean for him or her to die well, and what steps need to be taken in order to promote this outcome." (p. 1)

One way to help insure this is for the social worker to ask the client questions that will offer him or her options and some control over the process. Rabkin et al (1994) correctly note that it is far easier to believe in the right to choose the timing of one's death when the person is actively dying and when their remaining time is likely to be hours or days. The strength of this conviction is tested when the person is not acutely and severely ill but untreatable, and may have weeks or months to go before an inevitable death. Such a person may be able to survive physically but with such chronic discomfort and diminished hope for any good quality of life that he or she sees no reason to remain alive. Is this person entitled to say "enough is enough"? Many health care providers who work with terminally ill people believe so. Once the client has decided to discontinue medical procedures or drugs, often I.V. morphine is started with the double purpose of alleviating pain and accelerating the timing of death. After its initiation, there may be a period of alertness for several days, or even weeks, before death occurs. But often a person becomes unable to communicate once the morphine drip has begun. Therefore, prior to the beginning of a morphine drip the counselor or nurse should

look for opportunities to facilitate conversations between the dying person and his or her loved ones and family members.

Some key questions to ask are as follows:

- Do you feel that you are going to die soon?
- If so, how do you feel about this?
- How will you know you no longer wish to continue medicines, treatments or supplemental feedings? (It's important to reflect to the client that what he or she feels is intolerable may in fact change. Most people with AIDS surveyed felt that blindness, dementia and incontinence were hall marks of life not being worth continuing.)
- Do you prefer to die at home, in a hospice or hospital?
- Whom do you wish to be with you?
- Would you like to have a clergy person make a final visit?
- Is there anything you haven't said to your loved ones?
- Is there anything else you need to do or complete?
- Have you thought about letting go since it seems to me that you're suffering a great deal?

Some salient points for significant others to consider in conversations with a person who is dying are as follows:

- Is there something you haven't said?
- Are there things you need to say?
- Have you told the person that it's okay for him or her to go now?
- Tell them what specific things or events will always make you think of them.
- Remind him or her of a special moment you two shared that will be with you forever.
- Tell him or her that you love them, and thank them for the relationship you had.
- Say "goodbye" and how much you'll miss them.
- Assure them that though you will miss him or her that you will eventually be alright.

Potential Barriers to Successful Intervention

The major obstacles to beginning work with people with HIV or AIDS is the social worker's own degree of discomfort with a variety of issues. First may be discomfort with members of sexual minorities, specifically gay men, or with racial minorities or people who have used illicit drugs. These prejudices all must be

acknowledged in order to be addressed. Second, as social workers, like most people, we have internalized an illusion of our own immortality. Working with young people who are dying forces us to confront our own mortality, which is a formidable task for any human being. Third, it is extremely painful to have to work closely with someone who is becoming progressively sicker and deteriorating physically. Yet it is precisely by facing these challenges directly, that each social worker has the opportunity to grow enormously professionally, personally and spiritually.

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