

Antrocom 2010, vol. 6, n. 1	79-89
	Antropologia Fisica

Psycho-Social Aspects of AIDS as a Chronic Illness: Social Worker Role Perspective

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INTRODUCTION

Illness is an inevitable fact of human life. Man does not live in a vacuum. Therefore, like all other events of his life, illness is influenced by socio-cultural as well as biological factors. Illness refers to biological, psychological or social conditions that are often understandable in a social or cultural context. According to Kleinman (1988) “illness refers to how the sick person and the members of the family or wider social network perceive, live with and respond to symptoms and disability.” Disease, on the other hand, is the problem from a practitioner’s perspective. In the biomedical model, disease refers to an alteration in biological structure or functioning.

The major focus of medical model is disease which refers to the state of non health and biological dysfunction only. It neglects condition of critical causal factors in health and illness. Along with the biological dysfunctioning, illness often brings psychological stress or social incapacitation. For example, a patient of end stage renal disease (ESRD) may have unpleasant physical symptoms due to accumulated fluids, metabolites and waste products. In addition to the physical discomfort, the patient may face enormous psychological stresses that affect his quality of life. The illness and its treatment (dialysis) can affect his family and married life, can reduce his ability to work and enhance the chance to be burnout, and can diminish the social support.

Illness is influenced by society or culture. As Klienman (1988) suggests, cultural orientations organize our conventional common sense about how to understand and treat illness. An ill person is one whose actions, ability or appearance does not meet social norms or expectations within a given culture regarding proper behavior or appearance. According to the sociological model, illness is a moral status referring to conditions or behaviors deemed undesirable by powerful social groups (Weitz, 2001).

As an alternative to traditional paradigms, biopsychosocial model has been emerged (Engel, 1977; cited in Kleinman, 1988: Ell & Northen, 1990). In this model, disease is considered as the embodiment of the symbolic network linking body, self and society. The biopsychosocial model is based on the general systems paradigm and proposes that disease and illness can only be truly understood by evaluating all potential contributing factors including the social and psychological context. From this perspective, illness behavior and disease are viewed as subject to genetic, biological, psychological, sociocultural and ecological factors.

In view of the above discussion, it could be said that as man is a social being rather than a biological specimen, illness can not be separated from his psychological, social or cultural context. Therefore, there is a need to view a person holistically to understand his illness and to focus on the role of individual health behaviors, and lifestyles and on social, cultural and institutional environments as they jointly and interactively affect individual and community health.

To understand and describe the interaction of chronic illness and the family, illness can be defined in system terms. In other words, the essence of an illness could be comprehended in psychosocial terms that will provide a useful guide for both clinical practice and research (Rolland, 1994). Rolland (1994) recommended bridging the gap between biological/medical world and the

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personal/psychosocial perceptive of chronic illness. A psychosocial typology of illness by Rolland (1994) categorizes a wide array of chronic illness in terms of onset, course, outcome and degree of incapacitation. To understand and categorize AIDS as a chronic illness, Rolland's psychosocial typology will be useful.

Ironically, AIDS is a kind of chronic illness that not only ends with the termination of life but also has a long term impact on the day to day living of the patient and his family and that can make the person physically, psychologically and socially disabled. AIDS is a particularly deadly disease, an illness with a fatal end

that destroy a persons immunity against infection, thereby leaving the individual defenseless against a variety of afflictions like cancer, pneumonia, and a host of viruses. Considering Rolland's psychosocial typology of illness, AIDS has a gradual onset rather than acute one, that means it presents a long term stress on the person and family and requires slower change or role adjustment. In terms of course of illness, AIDS has a progressive course that is continually symptomatic and increases in severity. After the diagnosis of AIDS, the disability increases step by step and the periods of relief tend to be minimal. Families of AIDS patients need to be prepared for continual adaptation and role changes. Increasing strain of family caregivers may caused by both the risks of exhaustion and the continual addition of new caregiving tasks over time. Professional help or institutionalization could be needed. However, it is not uncommon for a person with AIDS, to progress at different rates (Gant, 1998).

Currently there is no cure for HIV/AIDS and it is clearly progressive and always fatal. As it is a life threatening illness, an ill person fears an end to life before his or her life plan can be completed. The expectation of permanent loss of the loved one can make it extremely difficult for a family to maintain a balanced perspective.

The different kinds of incapacitation imply sharp differences in the specific adjustments required of a family. AIDS is an illness which can result both physical disability and social stigma. Sometimes AIDS patient can be physically disabled due to severe weight loss and extreme fatigue. Sometime it can be so debilitating that the person become incapable to holding job. AIDS is a socially disabling illness because of the combined effects of its perceived high risks of transmission, its long asymptomatic incubation period, its current status as incurable, and its links with highly stigmatized groups in our society - homosexuals and users of intravenous drugs. People with AIDS often experience enormous handicaps related to stigma as they may lose their jobs, health insurance, family and friends and general sense of self-worth (Rolland, 1994, p.31).

Considering the uncertainty or predictability, AIDS has predictability as it is a fatal disease and has a clear end point, but the timetable for getting there is very unpredictable. Advancement in medical technology and invention of new drugs and therapy (e.g., HAART) has prolonged the existing trajectory of HIV/AIDS, which implies a long-term individual and family adjustment and coping.

The rest of the paper will be divided into two sections. In the first section, the psychological and socio-cultural impact on HIV/AIDS will be discussed. The second section will focus on the role of a social worker to help alleviate the stress and sufferings of an AIDS patient.

IMPACT OF HIV/AIDS

HIV infection and AIDS, like other life threatening illness such as cancer and heart disease, exact a tremendous physical and psychological price on their victims and others who are in the victim's social network. The person with HIV/AIDS will not only have to worry about health complications and the possibility or inevitability of dying, there may be disruptions in relationships with family, friends and neighbors, people at work or anyone the victim might meet. Living with HIV/AIDS presents unique problems that are not normally experienced by someone who has cancer or heart disease. Although social, economic or ethnic background can affect how someone copes with HIV/AIDS, most of the HIV infected persons, if not all, will have to confront major social issues

that include who to tell about the infection, how to deal with possible disapproval or rejection, how to cope with the infection, how to find new meaning of life under the threat of a potentially life threatening disease, and whether to pursue life as normally as possible or withdraw from social interactions and relationships (Derlega & Barbee, 1998). Reactions to the HIV-positive persons are influenced by cultural norms and stereotypes about behaviors associated with the transmission of HIV.

The diagnosis of HIV infection is regarded as a traumatic event. HIV/AIDS is a trauma in that it is “out of the ordinary” and experienced as a threat to survival and self-preservation, and is ‘markedly distressing to almost anyone’ (Schonnesson, Ross, 1999, p.35). HIV is also a traumatic event in that the individual is confronted with various threats or stressors that may draw the individual into a realm of hopelessness and powerlessness.

HIV/AIDS as a Threat to Physical and Psychological Survival

The individual’s physical survival is abruptly challenged by the diagnosis of HIV/AIDS, and his life is disrupted as the disease penetrates into the immune system, blood and the semen. These vital fluids also have a symbolic meaning of life. Blood is the symbol of feeling alive, passionate, being inextricably connected. Semen represents life and its continuity and the immune system the protection of life. The infection illuminates our fragility on human beings and life’s finitude through death, the one certainty of our lives (Schonnesson & Ross, 1999, p.35).

Enormous progress in medical treatment over the years has accomplished to manage and postpone HIV related symptoms and diseases, but the infection is still not curable. However, as a result of medicine like AZT, Videx, protease inhibitors and recent combination therapy, life expectancy for people with HIV/AIDS is much longer today than a decade ago. The medical technology has introduced a new concept of “long term nonprogressor” which refers to people whose HIV-positive serostatus has been established unequivocally yet who remain immunologically healthy and physically asymptomatic for 12 years or longer. The time span has also changed with respect to survival after being diagnosed with AIDS.

In the early 1980s, gay men with HIV were in general told they would live, at the most, another year or two, and as a consequence of the perceived “death sentence” some of them decided to quit their jobs in favor of disability or sick leave. But quite a few of these men have remained quite healthy over the years being long-term nonprogressors (Schonnesson & Ross, 1999). Ironically to some people it is more or less a burden to be a “long term survivor”. After being diagnosed with HIV, the person may see other HIV-positive people die and may develop a feeling of “survival guilt”. Regardless of being a long-term nonprogressor or long-term survivor or not, people with HIV/AIDS must live with various physical threats. These include stressors such as uncertainty and worries about the disease progression and its potential patterns of HIV-related symptoms and diseases.

To understand the meaning of physical threats, Rolland’s (1994) time phases of illness will be useful, as the types of social issues that HIV-seropositive person face may differ according to the progression of illness in different time phases. In the “crisis” phase, when the person diagnosed with HIV, he/she may be asymptomatic but become worried and concerned about the progression of the disease. In this stage, people might ask themselves when they would get sick or become concerned about what kind of symptoms they might develop. In the chronic phase, i.e., the time between the initial diagnosis and readjustment period and the terminal phase, the HIV-positive people may face mild symptoms or severe symptoms. However, the meaning or the impact of the illness can not be grasped by simply knowing the biological behavior, rather, it is a more psychological construct which Rolland (1994) referred as “the long haul” (p.49). The meaning of physical threats may change from uncertainty to fear about current and potential bodily

deterioration in this stage when the patient exhibit general and nonspecific symptoms such as persistent fatigue, rashes, night sweats and unintentional weight loss. It is common in this phase that the people also fear about losing control over their lives because of the illness. In the terminal phase, the fears about the disease are confirmed and end of life becomes a reality.

HIV/AIDS also threatens the individual's psychological survival because of the close link between the body and the self. Our body is also important to the self-image and self-esteem. When HIV/AIDS attacks the body, fear of losing one's self and self-esteem and ultimately dying psychologically is evoked, along with the fear of physical death. Our bodies also play an important role in our striving to be affirmed and acknowledged as a sexual person. People with HIV may experience their sexual self-esteem being heavily affected because their bodies do not match the image of a "perfect body". Dementia or any brain lesions constitute a terrifying threat toward psychological survival. A HIV-positive person indicates that "I am terrified that the virus will attack my brain, because if it does that means that I would just vanish as a person" (Schonnesson & Ross, 1999).

The Social and Cultural aspect of Being HIV-Infected

Although it is stressful enough to have a life-threatening disease like cancer or heart disease, individuals diagnosed with HIV/AIDS also face social challenges based on the cultural view and society's reactions to this deadly disease. While disclosing HIV seropositivity to others may be associated with acceptance, caring and social support from others, it often leads to rejection and discrimination by others. It may also bring distress for the family of the HIV seropositive person.

A major aspect of coping with HIV/AIDS is the possible stigma associated with being diagnosed with HIV/AIDS. Dealing with the stigma of AIDS is one of the primary challenges and sources of stress. HIV-infected individual must cope with the possibility of other's disapproval, rejection or even moral revulsion, especially if they are perceived to have contracted the disease through behaviors (e. g., male same-sex behavior, injection drug use) that are disapproved by the society at large.

AIDS related stigma is manifested in a variety of ways, HIV-infected people continue to be rejected by friends and relatives, fired or forced to resign from their jobs and subjected to violent assault (Herrek, 1990). Although every society have specific criteria that determine the degree of which people are accepted and embraced versus rejected and shunned, the stigma related to HIV/AIDS appears to be almost universal. Why HIV/AIDS is stigmatized in almost all over the world? First, HIV/AIDS is perceived to be a threat to health and safety. To the extent that HIV/AIDS is contagious, fatal and presently incurable, many people hesitate to interact with persons known to be HIV-positive, despite repeated reassurances by the medial community that HIV is not transmitted by causal contact. Not surprisingly, the more contagious people believe AIDS to be, the more they desire to avoid people with AIDS. People with full-blown AIDS are more likely to be stigmatized than those with latent HIV because the visibility of the disease may be more likely to disrupt social encounters and lead to avoidance (Pryor & Reeder, 1993).

Second, people are less accepting of those who deviate from their own cultural norms, morals and values, and thus one basis of AIDS related stigma is that it is associated with some already stigmatized groups, such as gays, intravenous drug users and to a less extent, certain minority groups. Such groups are primarily stigmatized because they are perceived as deviated from prevailing standards. In fact, AIDS was initially identified in gay men and originally called "gay plague". It could be noted that some AIDS patients, for example, children and those who contracted the virus through blood transfusion, are viewed as "innocent" or "blameless" victims (Herrek, 1990).

Third, people with HIV/AIDS often can not meet their occupational, family and social obligations as fully as they did before they were infected. Many tire easily, must miss work for medical reasons,

and during the later phases of the disease, require assistance from other people. People who are HIV-positive may be viewed as peripheral social contributors who drain more emotional, financial and practical resources from others than they contribute. Unfortunately, such perceptions lead to stigmatization.

Forth, it is observed that having HIV/AIDS makes others feel uncomfortable, awkward, and anxious and it brings to mind negative affect or aversive emotions. Aside from the fear of contagion, interacting with a person who has suffered a traumatic event like AIDS, can be disturbing. Many people may be uncomfortable interacting with someone known to have a terminal illness like AIDS, and a possible reason of this could be that it may force people to confront their own mortality. Thus, disassociating from the AIDS patient may simply be a means of reducing one's own anxiety (Herek, 1990; Pryor & Reeder, 1993).

Consequences of Stigma related to HIV/AIDS

As a fatal and incurable disease HIV/AIDS creates immeasurable psychological distress and markedly changes how one approaches life. Along with all of the direct effects of the disease on the person's well-being, the person with HIV/AIDS must deal with the stigma related to this disease. Many HIV-positive people report that dealing with the stigmatizing consequences of the disease is one of the primary problems that they face.

The stigma related to HIV/AIDS often disrupts the interpersonal relationships of the person with HIV/AIDS. People often shy away from the disease, often do not touch or shake hands with HIV-positive person, drawback from them, stare at their visible symptoms, and many even vocalize revulsion or fear. Person with HIV/AIDS may be avoided by their friends, family, neighbors and coworkers; they may be driven from their neighborhoods or be fired from their jobs (Herek & Glunt, 1993). Because they fear these sorts of rejections, people with HIV/AIDS often conceal information about their condition from the people in their lives. Fearing rejection, people with AIDS may contribute indirectly to their social isolation.

Another dismal consequence of HIV-related stigma is that sometimes the family and friends of HIV-positive person may reflect their negative reactions. Even if those who are close to the infected person do not personally stigmatize HIV/AIDS, they may fear that they themselves will be stigmatized by others for being associated with HIV-positive person. Sometimes spouses, children, family and friends of AIDS patient may be denigrated by their association. In other words, being associated with a stigmatized person like AIDS patient is itself often viewed as grounds of being avoided. Because of the fear of being stigmatized by association, family or friends of people with HIV/AIDS and the caregivers in particular, tend to distance themselves from the infected person.

Due to the stigma related to HIV/AIDS, people with HIV/AIDS and their family or friends tend to keep the HIV status secret. In fact, it becomes a faceless disease, as John (1998) stated:

“As a newsman I have waited for the day when someone will stand up and be prepared to be named and photographed as he tells his story, we need to put faces to people with HIV and AIDS, to make the point that they are not monsters, they do not need to be shunned, and they do not deserve their fate, no matter what they did to get infected”.

AIDS related stigma may linger even after the affected person has passed away because the cause of the death was AIDS. As a result, survivors often try to conceal the true cause of a loved one's death. The stigma related to HIV/AIDS influenced the research and policies. Even before the year 2000, in Singapore, people who die of AIDS had to be buried or cremated within 24 hours. The stigmatization of AIDS has impeded governmental support for research and treatment (Herek & Glunt, 1993). Fortunately, not all interpersonal consequences of AIDS are negative. Some infected persons report that their relationships with lovers, friends and family actually deepen as they show their explicit love and concern for the infected person. In some cases, people treat those with AIDS

as if they were something special and particularly desirable. Magic Jonson and Arthur Ashe are examples of people who appear to have gained even more positive regard after it was learned that they had AIDS. HIV/AIDS related stigma has tremendous psychological consequences too. Persons who are stigmatized as HIV-infected experience a range of negative emotions including depression, hostility, anger and anxiety. Being avoided or rejected by other people can be a painful experience. People with HIV often report feeling excluded, isolated, estranged, alienated and lonely. HIV-infected person often assimilate society's stigmatization, perceiving themselves as contaminated and worthless. At the extreme, stigmatization has been identified as one of the psychological stressors that may lead AIDS patient to commit suicide.

Ironically, the stigmatization associated with AIDS may actually affect the health of the infected person. Fear of being stigmatized and rejected leads some people to resist being tested for HIV (Herek & Glunt, 1993). Failing to disclose the HIV positive status deprives the infected person from social support. Person with AIDS bear the burden of societal hostility at a time when they are most in need of social support.

Gender aspect of HIV/AIDS

Gender norms significantly affect an individual's risk and societal vulnerability to HIV/AIDS because they ascribe distinct productive and reproductive roles to women and men (Campbell, 1995, cited in Habib, 2004). Various factors are directly or indirectly related to gender that place women at increased risk of exposure to HIV infection. Women are specially vulnerable to HIV/AIDS as they are unable to negotiate safe sex and are vulnerable to sexual exploitation. Moreover, social and psychological burdens are greater for women than men and women's social position makes it difficult for them to undertake preventive measures. As for example, in Bangladesh, women have been socialized through religion, cultural taboo and other social mechanisms to accept sexual subordination and even sexual oppression. They are often precluded from most basic means of prevention (e.g., safe sex). Lack of AIDS knowledge and lack of bargaining power with their sexual partner are one of the many factors making them susceptible to the transmission of HIV/AIDS (Habib, 2004). Many African women also face the similar situation (Cockerham, 2000). However, as regard to the stigma related to HIV/AIDS, HIV-positive women are less stigmatized than HIV-positive men, because people are more likely to assume that a man with AIDS acquired the disease through 'deviant' behavior, especially male same-sex behavior (Leary & Schreindorfer, 1998). Ironically, research has suggested that women with full-blown AIDS die quicker than men with AIDS (Kolata, 1987, cited in Shernoff, 1998).

SOCIAL WORKER ROLE PERSPECTIVE

AIDS is a disease of society, as it is clearly grounded in the conduct of social life and it has the potential to change the norms, values, sex habits, life style, future plans and the relationship with life itself. It is a lethal disease with far-reaching implications for individuals, families, communities, health care providers and delivery systems and societies at large. Living with HIV/AIDS is a shattering experience for an individual. Social Workers enter into relationships with persons, families and communities to assist them in issues of daily living by providing them with an environment that will enhance their own skills and development (Wright, 2000). Social Workers can thoroughly assess psychological aspects of a HIV-infected person and his/her life story and create environments that will increase the person's understanding and thus strengthen the ability to cope with the stress and sufferings and adapt with the complex reality of life.

To discuss the stress and sufferings of a HIV-infected patient and the role of a social worker, we will use the biopsychosocial model as we assume the individual, family and illness as interacting systems. In the following discussion we will consider the psychological or behavioral response of

the person with HIV (PWH), his social interactions and also the courses of the illness. We will divide the social worker's role into two parts, as psychosocial assessment and counseling. However, these two parts should not be performed one by one. Rather, the assessment is an ongoing and dynamic process that allows for the changes and adaptations throughout the helping process.

Psychosocial assessment

Assessment is the cornerstone of social work practice (Wright, 2000). By thorough assessment, a social worker will gather information about the PWH's physical and psychological functioning and about the social environment in which the person lives. According to Wright (2000) there are four areas that are essential to an effective and practical assessment of a PWH's psychosocial functioning, which will be briefly discussed below.

A thorough evaluation of the context

It is very critical for a thorough assessment process to consider the context or environment where a PWH lives in. As HIV/AIDS is a socially constructed disease, it depends on the environment/context that how a PWH will be accepted in the society and how will be his quality of life after being diagnosed with HIV. Social workers should assess the socioeconomic status of the PWH, his ethnicity, geographic location and most importantly the availability of social support which include interpersonal support, institutional support and also the community sentiment regarding HIV/AIDS. Interpersonal support includes family, friends and others in the community. Institutional supports include available, accessible, and affordable resources or services in the community such as medical or other health care services, health insurances etc. Social workers need to develop and create connections with the social services to get appropriate help for the PWH. Social worker could use her status and professional expertise to advocate with the service providers in order to arrange a comprehensive care for the PWH

The PWH's knowledge about HIV/AIDS

To help the PWH alleviate his sufferings and stress, it is important to assess the level of knowledge that the PWH has about HIV/AIDS, because, the social worker wants to make the PWH able to help himself, and for this the PWH should be aware of his medical condition. The PWH may not have the up-to-date and accurate information about HIV and inaccurate information or biased knowledge about the illness could be very dangerous. Therefore, the social worker needs to assess the level of knowledge of the PWH and if necessary she will provide him general information about the HIV/AIDS and particularly about the mode of transmission. She will assess the risk behaviors and counsel on safer sexual practices. This will help the PWH reduce the risk behavior. Being able to reduce the unsafe sexual practice or risk behavior will help the PWH have a sense of control over his life and also increase his self-esteem. Thus, a social worker will provide information, support and intervene with resources that will enhance the PWH's overall functioning.

Determine norms, beliefs, values and attitude of the PWH

The behavioral and attitudinal factors of the PWH are primary in the prevention, intervention and treatment of HIV/AIDS. Hoffman (1996, cited in Wright, 2000) provides some area that should be explored which include attitudes and beliefs related to HIV transmission, barriers to risk reduction and sexual self-efficacy. To assess these areas, social worker will ask about the sexual history the PWH or about the substance use.

Determine beliefs about sickness and health

The social worker needs to know the PWH's belief about illness and health, particularly how the

PWH defines sickness because this will influence the process to approach the PWH. The social worker needs to know what does being HIV-positive mean to the PWH, what the person believe to be the cause of his illness (e.g., a natural cause, a curse or punishment?) and what is the PWH's fears about being HIV-positive. These beliefs are important because it influence the coping process of the PWH. In addition, the understanding of a person's spiritual beliefs, including death and dying, and how these beliefs stimulates the PWH's coping styles and behavior will expand the resources for support to be explored. Considering the spiritual beliefs of PWH is important for assessment and intervention. For instance, PWH may feel anger, shame, guilt, depression and loss of control as a response to the diagnosis of HIV. To cope with these negative feelings, a powerful coping strategy could be to strengthen the faith in his spiritual beliefs. Tying up the above discussion, we could see that in order to help a PWH social workers need to do a thorough assessment to gather information about the psychosocial function PWH, his medical status, financial condition, coping style, his beliefs about illness and death which will be useful in counseling and intervention.

Counseling a Person with HIV (PWH)

Along with the initial assessment, the social worker can do supportive counseling in order to help a PWH alleviate his stress and sufferings. The counseling focuses on physical, psychological, social and spiritual aspects of the PWH. It involves the discussion of disease progression, discrimination and stigma related to HIV/AIDS, death and bereavement issues, life style, safer sexual practices and living positively with HIV/AIDS. Through the counseling, the social worker will help the PWH to identify concerns like disclosure of HIV-positive status, identify risk behavior, practice safer sex and substance abuse; will enable PWH to identify and express his feelings and to develop coping strategies to adjust with the current situation.

Some important aspects of counseling a PWH are discussed below.

Living with HIV/AIDS versus dying from AIDS

Due to the advancement of medical technology, we are now familiar with the term 'long term non-progressors' or 'long-term survivors'. Therefore, while counseling a PWH, the social worker can help the client balance a realistic sense of hope with practical issues inherent in learning to live with HIV/AIDS. When a newly diagnosed PWH will hear from the social worker that there is usually a period that increasingly last up to ten or more years where people remain asymptomatic, it will help him or his family internalize some hope in adjusting to the diagnosis of HIV. Hearing from the professional that the diagnosis is most often is not a death sentence, could be a very empowering experience for the PWH. Thus, when a social worker will tell the client that he is currently living with HIV, not dying from AIDS, it will be beneficial for the PWH and his family.

Supportive denial

Supportive denial means that the client will not keep an awareness of his/her condition in the forefront of his/her thoughts at all times (Shernoff, 1998). Denial itself is neither bad nor good. If the client's denial is so pervasive and intense that it impairs the PWH's reality testing, then the worker needs to challenge this denial. As for example, when the PWH denies that that he is, in fact at risk of contracting or transmitting HIV and therefore refuses to change either sexual or drug-taking behaviors in order to protect others. Denial should be assessed according to its outcome. If the denial contributes to an adaptive mode of living with HIV/AIDS, then the worker should not challenge it.

Mobilizing the family

In the case of HIV/AIDS, an illness that is so emotionally laden, family conflict and stress often run

high. Families of the PWH need encouragement and support to express hurt, anger and fear. Hence, the social worker needs to help families identify their conflicting emotions and help them make sense of their reality and begin to establish some control over their situation. A family genogram could be a useful tool to assess the personality and attitude of each member and understand the conflict and relationship among them. Social worker can also help families negotiate with care providers in order to receive accurate information about medical care, treatment options, nutrition and other available social services.

HIV disclosure and dealing with ethical issues

In the process of helping a PWH, the social worker may face some ethical dilemmas, as for example, whether to reveal a client's HIV status to his/her partner(s) particularly when the client refuses to do so. This type of situation leads to conflict with social work value of self determination and client confidentiality. To deal with this kind of situation the social worker can review the pros and cons of the options (i.e., to disclose or not) and should make a reasonable decision (Giddens, et al., 2006). In my opinion, here the partner's need to be informed about her potential risks outweighed the client's need for self protection. So the reasonable decision would be to disclose the HIV-positive status to his partner in order to reduce the risk of transmission. However, before making this decision, the social worker should motivate the client towards the decision and help him to achieve a sense of control and increase his self-esteem. The social worker can apply behavioral interventions to reduce risk behavior of PWH which includes condom use and communication skills training and development of a personal risk reduction plan (Wolitski et al., 2006).

Improve adherence to treatment

The successful treatment of HIV infection is heavily dependent upon medical adherence. Poor adherence contributes to the development of drug-resistant HIV, and high levels of medical adherence are associated with sustained reduction in viral load, decreased risk of developing AIDS, and enhanced survival (Natasha et al., 2002, cited in Wolitski et al., 2006). If the PWH have poor adherence, the social worker would encourage him, provide support and information about the needs of the medication. She can help the PWH communicate with physicians and other health care staff by bridging the gap between them. This could ultimately be helpful in increasing the treatment adherence of the PWH.

Preparing for serious illness

Though we have assumed that the client is newly diagnosed with HIV, counseling and preparing him for serious illness would be useful in overcoming the unforeseen but inevitable health crisis. AIDS-related illness can have an astonishing sudden onset. Often clients and their families are ill-prepared to cope with decision that could have been discussed prior to the onset of a medical emergency. Therefore, it is good to discuss some issues, though difficult and painful, long before there is any apparent need for them. The social worker could discuss the issues like which hospital the client wants to be taken to in case of an emergency, who will be contacted in crisis and the sensitive issues like advanced medical directives (AMD) and about a health care proxy (Shernoff, 1998). In fact, when the client is well, he/she is more likely to have the necessary energy for planning these difficult realities. The worker could introduce these issues by stating that although it is too early to start thinking about these difficult realities, addressing these issues now will ensure that the client will have a control over what will happen to him. This will help the client feel better. In view of the above discussion, it could be said that as social workers we can help a person with HIV/AIDS to learn to adjust and live with this life threatening illness and to deal with issues that

have emerged with the diagnosis of HIV. To be able to help a PWH, the social worker should be well-educated about HIV/AIDS. As HIV/AIDS is a socially constructed disease, the social worker should be aware of cultural norms, values and stigma related to HIV/AIDS and should also be prepared to deal with issues like death and dying as HIV/AIDS is a fatal disease. One of the most important roles of the social worker will be as liaison between the PWH and his/her family, between the PWH and physician or other health care providers and between social service agencies. Last but not least, in working with a stigmatized disease like HIV/AIDS, the social worker should always apply the basic social work values: respect the worth of each individual and non-judgmental attitude.

Persons living with HIV/AIDS must adapt to a disease that promises multiple changes in every aspect of their lives. HIV/AIDS not only brings health complications and inevitable death, it also brings enormous psychosocial stress and stigma that can shatter one's life. At the twenty-first century, when we have tremendous medical advancement in treating this disease, we hope HIV/AIDS to be treated like any other illness. As social workers we have the responsibility to respond to the person with HIV/AIDS who are in need of comfort, reassurance, compassion, and love. Working with persons with life threatening illness and engaging in issues as psychosocial functioning, sexuality, spirituality, dying and death, which are all inherent in AIDS, are invaluable clinical skills that are relevant to all aspect of social work practice with any client population.

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