Self-determination and Uniqueness:
The Challenge of the HIV-positive Drug Addict

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Abstract

The role of self-determination and respect for the uniqueness of the individual is explored as it relates to the distinctive cluster of attributes found among drug abusing HIV-positive clients. The author describes the development of personal values and the challenge that two client populations have presented in that personal development. First, experience working with substance abusers in agency and institutional settings is described. The relevance of that experience to case management of clients who are HIV-positive and experiencing drug abuse problems is then demonstrated. Challenges and ethical dilemmas are noted. Finally, the impact of combined negative behaviors, various stigmas and the social worker's response to these is outlined, with a call for addressing this issue as individuals and as a profession.

Challenge of the HIV-positive Drug Addict

Allowing self-determination and respecting the uniqueness of the individual are basic values in social work (Hepworth & Larsen, 1990). I have been blessed with learning experiences that have increased my ability to demonstrate those behaviors in my relationships with others. I am becoming convinced, however, that there are limits to that ability and that I have an ethical responsibility to address the issue. It is important that I be able to accept self-destruction as a choice and to accept clients who present a cluster of uniquely negative behaviors if I am going to serve HIV-positive drug addicts, currently the second largest population of individuals with AIDS (Hammett, Hunt, Gross, Rhodes & Moini, 1991). This is my challenge and, because of the scale of the problem, the challenge of social work as a profession.

I was raised in a home where the worth of all individuals was valued. We attended a church where the ministry and congregation joined in the battles against the Vietnam war and for the civil rights of all our citizens. I was also steeped in the idealism of the 1960s, when everything appeared possible and no barrier insurmountable. I have always wanted the best for others, and for many years I was convinced I knew what that was. What one needed to do to secure happiness was so clear to me that I could not imagine being unable to recognize it. I had not yet grasped the concept of self-determination.

It is only through my work over the past five years with predominantly involuntary clients that I have come to recognize the critical importance of allowing clients self-determination, regardless of their choices. My recent work with the case management of HIV-positive clients has pointed up a major challenge facing us in social work. A large segment of new HIV-positive and AIDS cases is composed of drug addicts (Hammett, et al., 1991). This is a group that is extremely difficult to help, and presents us with a formidable challenge as we try to provide the help they so desperately need.

In recent years I have realized just how significant were the values I was introduced to as a child. Not every child is taught that the color of a person's skin does not determine her or his worth. Not every child is taught that it is the responsibility of all people to advocate for those discriminated against. It is not every child that becomes a part of what their parents perceive as the solution. As a ten year old, I followed my parents as they led us from the relative tranquility of

the northwest side of Detroit into the turbulence of the central city. They were convinced that they needed to demonstrate their beliefs, and demonstrate their beliefs they did.

This move to the heart of the city offered me a multi-cultural context in which to grow, and to this day has allowed me comfortable interactions with people from a range of backgrounds. The neighborhood to which we moved in 1960 was Black and White, Asian and Arab, lower middle class and poor. A diverse backdrop for life! Seven years later it also offered a taste of the terror that violence can bring into our everyday lives. I experienced the troops and gunfire, the fear and surreality of the summer of 1967. The madness echoes in my memory.

Over the years since, I have traveled and been introduced to further expressions of the diversity of human existence. I lived for a number of years in San Francisco, where I was reminded daily of the variety of ways sexual identity is manifested. It presented me again with a rare context for living, where neighbors, co-workers, fellow students and friends displayed the diversity of choice and revelled in their individuality.

Several years living in Los Angeles introduced me to the quickly-growing Hispanic population. For the first time in my life I heard another language spoken regularly and other cultural norms expressed on a large scale. Again, this was no distant group, but a large segment of the total population and a large segment of those I interacted with on a daily basis.

In 1986, the year I returned to college, I began working in a series of agency and institutional settings with substance abusers. It was in work with these clients that I gradually became aware of some of my deficits in working with troubled individuals. I discovered in a rather lengthy process that I was frustrated in my efforts to promote change in the clients' behavior. I found that I also valued control over my environment, and I gradually realized that I had little control over the behavior of others. I still benefited from my earlier experiences with diversity, but was simultaneously hobbled by these newly discovered behaviors. Clients would change, but not in ways I would have chosen, and interactions were filled with surprises.

The process of not only recognizing but also addressing these shortcomings has been a gradual and difficult one. I worked full-time with these clients for three years before I finally began to allow clients the unfettered opportunity to make their own choices. I worked for five years with these clients before I was able to accept their choices. I discovered along the way that I have had

not only expectations of others, but altogether unrealistic expectations as well. Five years ago there was no way that anyone could have come up to my expectations. I am grateful that I no longer bring those to each and every client interaction.

Long ago I was blessed with an awareness of the common rights and worth of all people. These lie as fundamental values in social work. I have had a varied and wonderful experience of everyday folks from all walks of life. I had not been pressed at any point in my life, though, to move from the abstract to the specific with an extremely difficult population. Accepting the diversity of human beings–the uniqueness of each–becomes more difficult when they exhibit characteristics that rankle. For me, it is now a natural response to accept people of color (or the lack thereof), diverse sexual orientation and cultural background. There are others, however, who present a more difficult challenge for me. These are people whose differences are negative, referenced to commonly-held moral, societal or personal survival standards.

This is a deeper challenge. Assuming I am able to accept some aspect of the client's behavior that I perceive as negative, the question then presents itself as to how many of these can I accept simultaneously. Is it possible to accept a cluster of values, attitudes or behaviors that I perceive to be negative, and continue to treat the client with respect and to provide the needed services? At what point is the unique individual uniquely unacceptable? At what point do I become overwhelmed with fear or revulsion and ineffective in providing services? I am beginning to believe that for myself and for each social worker, there is such a point. I am also coming to believe that this bodes ill for one rapidly expanding client population that desperately needs the services and the empathy only social workers are likely to provide.

My work with drug addicts and alcoholics has revealed a cluster of negative attributes they bring to their relationships with service providers. Rebellion is at the top of the list. There is a tendency not to do anything they perceive as mandated. This is true of voluntary clients but is epidemic among involuntary referrals. There is also a great deal of anger and it is manifested overtly in outbursts but also covertly through implied physical threats and other subtle behavior. These are not always recognized, but in my experience they are a consistent aspect of interactions.

As one moves to low-bottom substance abusers, such as late-stage alcoholics, intravenous drug addicts and those addicted to crack cocaine, another set of problematic behaviors is

encountered. Many clients in this group have had frequent arrests and have spent time in jails and prisons. They bring a prison value system with them to treatment, which emphasizes not revealing feelings or vulnerabilities. It also calls for a swift and violent response to threats. Additionally, there are frequent health problems resulting from the years of substance abuse that produce physical aches and pains upon the withdrawal of their drug of choice. A low tolerance for pain of any kind, be it physical or emotional, characterizes the long-time substance abuser. The entire lifestyle is built around one imperative–to kill the pain.

Educational levels are extremely low among individuals in this group, and fundamental reading and writing skills may be entirely lacking. There is brain damage related to their substance abuse that impairs their ability to think, emote, and remember (Gorski & Miller, 1986, pp. 57-65). All of these final deficits sharply reduce the possibility of successfully treating this population. My experience is that the above-listed issues are manifested in the behavior of long-term substance abusers. Bob illustrates some of these difficulties. He came to treatment following 14 arrests, covered with tattoos and stating from the start that he is violent when drinking. He completed the eighth grade in special education classes and is functionally illiterate. He has spent a number of years in prison and is currently on parole. Bob came to treatment at the request of his parole officer, and does not believe he has a substance abuse problem. These attributes all complicate the helping relationship.

As the welfare of the client is uppermost in my mind, I have had to ask myself whether I am capable of helping this population of clients. To date I remain convinced that I am, but working with substance abusers generally is a daunting task. Not only are they a difficult group of clients to help, but success is rare. Addiction is a disease prone to relapse. Statistics reflecting success rates range over so broad a territory as to be meaningless. Anyone working in the field, however, would testify to a small fraction of successful client recoveries. Difficult though they may be, this is not the most difficult of client populations that we can serve.

As Pray (1991) has noted, respecting uniqueness is a fundamental value of social work, and yet difficult to operationalize. Experience during my internship at an agency providing case management for HIV-positive individuals has raised my awareness that there are limits to our ability to accept. We can collectively ignore this, wishing it were not so, but a wave of extremely difficult cases is arriving every day to challenge that approach.

Many, if not most, social workers are going to reach the edge of the envelope with this segment of this population. Drug addicts with HIV infections, in particular intravenous drug users (IVDUs), have become a very substantial portion of newly reported cases. "In the United States, nearly 30% of the over 39,000 adult AIDS cases reported in 1989 to 1990 were related directly to IV drug use (6% in combination with homosexual activity). Through 1987, 17% of cases had been attributed to IV drug use" (Hammett, et al., 1991).

In what ways does this change the receptivity of social workers to HIV-positive clients? It might be useful to note that the IVDU brings the stigma associated with drug addicts and criminals to an arena already knee deep in stigma. Never in modern times has a disease been so deeply feared. The popular press has been filled for years with stories of children run out of school, adults put out of work, families chased out of neighborhoods and people shunned by those once held dear. Fears persist that all possible modes of transmission are not yet known and that social workers' personal safety may be at risk (Wiener & Siegel, 1990).

Homosexuals, who constitute the majority population of those infected with HIV, have long been stigmatized and homophobia is still found in a substantial portion of social workers (Wiener & Siegel, 1990). AIDS has been seen by many Americans as an appropriate retribution for the sexual behavior of the homosexual community.

Over time, however, changes in the demographics of HIV-positive populations have occurred. "Whereas the infection was most frequently found in the gay, male community during the 1980s, it now has begun shifting to the inner-city, drug-abusing community" (Griffin, Lurigio & Johnson, 1991).

It is not only the stigma associated with the perception of the drug addict "as little more than a composite of reprehensible traits" (Singer, 1991) that she or he brings to the HIV arena. There has also been a shift in the racial profile of these individuals. Where the homosexual infected with the virus was typically white, the IVDU is typically an African-American or Hispanic. The varieties of racism in America and a lack of cultural awareness have been introduced as potentially complicating factors (Singer, 1991).

There are three primary areas of concern: the client's actual deficits, stigma attached to a cluster of attributes and the social worker's response to the combined deficits and stigma. It may

be useful to specify ways in which these problems might impact efforts to provide services to the IVDU who tests positive for the HIV virus.

First, the client will probably seek help late in the progression of the illness. Drug addicts as a group are not noted for rigorous health care. The average female client in one study had experienced one to three opportunistic diseases prior to seeking help (Stuntzner-Gibson, 1991). The opportunistic diseases such as Pneumocystis carinii pneumonia (PCP), Toxoplasmosis and Candidiasis typically occur in the latter stages of immune system collapse (Maxey, Gee & Omrod, 1988). There is a fair chance that the client will not be interested in abstaining from the use of drugs (Hammett, et al., 1991). The HIV infection will introduce additional psychic and physical pain, which many drug addicts will choose to numb with drugs. There may be no interest whatsoever in seeking treatment for their drug problems, and even if treatment is attractive to the client, access to treatment is limited. Some clients continue to use drugs right up to their deaths.

They will bring street and prison behaviors to the relationship with their social worker, which will complicate the efforts of the worker to establish the trust necessary for an effective helping relationship. These clients are conditioned to exploit weakness and will target vulnerabilities (Singer, 1991, p. 264). Some of them are periodically dangerous, as drug use is strongly associated with violence (Magura, Rosenblum & Joseph, 1991). There is also a tendency toward secrecy and dishonesty. Some of our clients have not been willing to reveal their names to the social worker because of existing legal issues.

Behavior we may judge to be uncooperative may result from mental deficits related to their drug use (Gorski & Miller, 1986), lack of education, or AIDS dementia (Maxey, Gee & Omrod, 1988). Whatever the cause, if the clients are unable to think, it can sharply reduce their effectiveness in advocating for themselves, and increase the need for the social worker to advocate for them.

The disease will also produce physical effects that will impact and complicate the relationship of the client with the social worker. There is a host of diseases to which the HIV infected individual is prone. Some of these will hospitalize the client. AIDS dementia, in which the virus invades the brain and spine, can result in confusion and the progressive loss of physical function. One opportunistic infection can result in open sores on the face. Extreme weight loss is common in the late stages of the disease. The client may endure severe diarrhea, abdominal

cramping, nausea, vomiting and appetite loss. (Maxey, Gee & Omrod, 1988). Worse still, the client may actually experience a number of these problems simultaneously. This barrage of illness can result in apathy, depression or suicidal ideations. In a relatively short period of time the client is likely to die, which presents yet another set of difficult issues.

Mike, an HIV-positive drug addict exemplifies many of the issues listed above. A cocaine addict, the client is developmentally disabled, with a history of depression. He has no family support and only substance-abusing friends who take advantage of his mental deficits. He has not cooperated with medical direction and is experiencing severe neuropathy which is painful and limiting his mobility. Mike also has a quick temper, poor hygiene, diarrhea, severe memory problems and has refused supervision. Although financial benefits have been secured, the money he receives each month is quickly spent on drugs and the client is left homeless.

I believe that we are facing several specific dilemmas as social workers working with this population. The first is to maintain respect for these individuals regardless of their background, behaviors, inability to cooperate in securing services, and unwillingness to seek treatment for their drug problems. There is every evidence in my interactions with clients that they cherish that respect. These clients are well aware of the multiplicity of stigmas they bear and the reactions they have experienced from others. Frequently they are isolated and the caseworker is the only person in their corner. These clients, through their behavior, however, can make a caring, empathic response difficult.

Accepting the clients' choices, whether those are self-destructive choices or productive choices, is another challenge. This group of clients is likely to act as if they were involuntary, although they have sought help themselves. They bring to the relationship a distrust of authority and a strong tendency toward rebellion. It can be frustrating to have a client doing absolutely nothing you have suggested, although that would certainly satisfy the definition of self-determination. My experience with involuntary clients points up the possibility of that happening. Even the most cooperative HIV-positive clients can produce a separate agenda of issues they feel most important, regardless of well-laid collective plans.

I come to social work as a profession, with a desire to help. In the course of learning how to offer that help I have been confronted with the need to grow and to change. My work with HIV-positive clients, and with others providing their care, has raised an abundance of issues. I feel I

must address these issues in order to provide effective services to the client population with whom we work. These are not abstract issues, but rather practical issues. How can I effectively provide care to people who manifest attributes I find frightening, repulsive or exasperating? Perhaps more accurately, how can I manifest respect for clients who exhibit characteristics in all three categories. I need to be honest about my fears, my values and my desires in order to work through these issues.

I was raised in a home and church that laid the ground for my value system today. The concepts that underlie those values are sound. The application of those values in this very real world, however, is no simple matter. The expanding population of HIV-positive drug addicts tests my willingness to grow. They represent an immense challenge: to stretch my ability to apply those values and to honor their humanity.

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