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# HIV/AIDS Psychotherapy - What Psychologists Need to Understand

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## Dealing With Diagnosis

Most people discovering they are HIV-positive quickly learn that they are not experiencing just a physical problem - complex mental, emotional, and spiritual aspects influence the quality and direction of daily life lived through the filter of HIV. Usually it turns out that it is not AIDS itself that is the problem (i.e., its medical definition), but rather what AIDS means inside one's mind, feelings, and spirit, as well as in the reactions of others. Such psychosocial factors accompanying an HIV diagnosis have much deeper influence than medical symptoms on the path each person's journey will take during the time they are living with the virus and trying to make sense out of it all.

*"My very first response to being diagnosed with HIV was immediate and emotional: I burst out crying... That's certainly not the kind of response that I was used to having. I wasn't used to showing a lot of emotion in my life. I come from a background of abuse and I learned to shut my emotions off, [so] this immediate response was very surprising to me, but also I guess very necessary" [F.H., p. 1].*

*"Ten years ago I tested positive and was told to make my will because I was going to die.... The news I got that day has changed my life forever, and I wake up each day knowing it." [J.E., p. 1].*

I didn't set out to become a therapist counseling people with terminal illnesses but found myself becoming an early "expert" as HIV increasingly emerged as an urgent issue among clients I was already specializing in treating (primarily from cultural minorities or societally marginalized populations such as Deaf, First Nations, gay and/or two-spirited men and street youth). Clients began to share with me their own HIV-positive status, that of loved ones, fears relating to it all, and so forth.

Revealing such things, even now years into the second decade of HIV is risky in itself because there is still no way to know how friends and family will react. There is serious import to the advice commonly given at diagnosis: "Once you tell, you can never un-tell". Once a person has divulged being HIV-positive, the perceptions or responses from others will never be the same; there's a new filter.

Because knowledge about AIDS and its various treatments is continually emerging, both medical and psycho-social truth is only situationally relative and prone to sudden changes or reversals without much advance notice. My clients find themselves frequently encouraged by their doctors to do things one way one day and then the next told to switch to something different. It's not that doctors are incompetent - they are doing the best they can when dealing with the unknown - its just that new information is being discovered literally daily.

*"When first diagnosed, when people are experiencing that immediate reaction, there are also a lot of accompanying emotions that go along with it... I think the biggest one for me, and the most prolonged response, was the shock - it is really something to all of a sudden hear that you have in your body this virus. You don't really know what it is going to do to you eventually... There is this big unknown that is probably the most shocking thing about being HIV-positive". [F.H., p. 1].*

This lack of firm foundation and frequent readjustment of reality frameworks makes it difficult to keep updated while counseling people infected or affected by HIV - and it's even more slippery for people living with the virus themselves to somehow make sense of it all while trying to activate coping strategies or realize life goals - especially as AIDS seems to be turning into a long-term manageable chronic disease. It is not uncommon for clients to be living a dozen or more years as HIV-positive and still healthy.

In HIV psychotherapy clients are dealing not only with those issues commonly expected in those facing death but also often those encountered in abuse. My clients often express feeling abused and disabled by virtue of having lost the majority of their own personal power or their right to exercise control over what is happening to their bodies and lives.

*"There is still a stigma attached to being diagnosed with HIV [and] AIDS. And I did feel dirty. I did feel ashamed that I had this virus. And I wasn't really sure at that moment when I heard that I was HIV-positive exactly how I was going to deal with it" [F.H., p. 2].*

This pervading uncertainty and lack of clear direction affects not just clients, but also us therapists, who are used to working within fairly predictable outcomes, whereby if we do things a

certain way, predictable results will likely happen. With AIDS., there has not been a lot of time to develop a sense of consistent direction, of learning what will most help clients (and ourselves) survive the limbo and find meaning in the chaos. Hopefully this article will begin to shed some light on what HIV infected/affected clients are experiencing psychosocially, as well as suggest some possibilities that might be of better help to them.

*"I was twenty. I made a list of all the things I needed to do in order to be able to consider my life a success before I die, and set out determinedly to pursue them. I got my education and excelled in my career. I found a partner and had someone to love and love me. I made healthy changes in my lifestyle. I had success until one day I got sick and had to quit work. I dealt with HIV fine until I quit work, and then the problems started. I lost the validation of it, the financial reward of it, the status of it. My health had deteriorated, and the dream seemed to be coming to an end."* [J.E., p. 1].

### **Psychosocial consequences of living with HIV**

Frequently, only the medical aspects of treatment or prevention are given attention, as if maintaining the body's physical health is the patient's sole responsibility, while far too often there is much less preparation for encountering, understanding, or coping with the numerous psychosocial issues that also arise. But the consequences of living daily with HIV, and its resulting limitations not directly connected to medical problems (such as poverty or relationship difficulties), are sometimes harder to deal with due to their more subtle and socially-isolating nature, particularly for individuals without a strong emotional support system through friends or family.

In truth, for most HIV-positive people, the problems encountered during the first several years are not medical ones; they are psychosocial. It is common for clients to explain that knowing they had tested positive was not the same as really believing it inside themselves - and thus the onset of their first illness often caused a second psychological crisis located somewhere midway between "positive visualization of ongoing health" and "denial". With HIV these two attitudes are often hard to distinguish between. With long-term survival becoming increasingly possible, most clients believe they will truly be the lucky one not going on to develop AIDS. And thus trying to get them to deal realistically with possible end-of-life issues may not be the goals most important to their health or stress reduction.

*"To me, over the years, I had a lot of losses that I've had to deal with. Some of them were familiar... The hardest loss that I've had to deal with was the loss of ability... [like] when I was on my back because I was sick and I couldn't do anything. I couldn't pick up the phone. I just didn't have any energy. I couldn't think, because my energy was just gone. That to me was the hardest thing to deal with, because that was not my character, my usual 'modus operandi' - not me. Ever since I can remember I've been an active person. I was always doing*

*something, like my grandfather used to do... [So] when I got to that point that doing anything was impossible, it was unbearable"* [F.H., p. 5].

Many clients express that it isn't being dead that worries them as much as the dying, and accompanying fears of being abandoned or consumed with pain in the process. Through therapy, they journey through life-review and life-closure issues, along with grief, anger, guilt (sometimes including survivor guilt), relationship difficulties, and resolution of "unfinished business" with family.

But these are also therapy topics with people who are not facing death; they are general health-enhancing explorations that can provide anyone with release from stress and self-empowerment in their activation of self-advocacy and proactive self-care. But with HIV-positive clients, each goal successfully accomplished still leaves the client dangling in an unfinished "limbo" where it's unclear whether to pause or keep living. If they only knew how long they were likely to live, they could make informed and sensible decisions; however, unlike cancer there's not such clear time-line expectations for prognoses. In HIV psychotherapy, psychological distresses such as depression or watchful anxiety can be seen not just as symptoms needing alleviating, but might instead be good indicators of needed and healthy grieving or necessary health vigilance in partnership with overworked doctors who must count on their patients to keep track of all the details.

*"People deal with HIV in different ways. Suicide-, denial... [and] I experienced anger. HIV is not easy to deal with. There is quite a feeling of depression that lingered in my life for a while. Not a deep depression, not a disabling depression, but this low level depression that didn't quite come out to the surface. But I was aware of it; I knew it was there. I didn't immediately jump into acceptance - I had to go through quite a struggle to get to a point - to get to THAT point. To get to the point of acceptance, to the point where I could publicly say, 'I have AIDS'. I was ashamed about that. [And] to get to that point that I realized that, I don't know when, but I'm going to die"* [F.H., p. 4].

The grieving for self and others never quite completes itself, as anticipatory grief and compassion fatigue overwhelms any attempt at dealing with death and emotional loss on a one-by-one basis like pre-AIDS life, where there was time to get over one loss before another arrives. Loss of others is difficult enough; however, with HIV gnawing away at one's abilities and lifestyle, "loss" has deeper meaning and cuts a wider swath.

*'Now that I was HIV-positive, believe me, this is a whole new journey in losses. That is probably the one concept that all of the emotional and psychosocial issues that I had to deal with - is that dealing with all the losses.. First off, right at the point of diagnosis, is the loss of status. We may have a very high position... in society, but if you are HIV-positive, this is gone*

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right now. You do not increase your status if you are HIV-positive" [F.H., p. 3].

Many clients tell me that it's hard to have AIDS-free time, that, as one client explained, "It's always there on my shoulder, riding along with me wherever I go". AIDS "tenderizes" people, making them vulnerable in sudden unexpected ways, and yet often much less willing to again risk being open to feelings of intensity of any kind. Clients tell me that they feel more free being "out" with HIV, but that once having done so, they find it difficult to get others to treat them like ordinary people. A client told me that he feels his friends are watching him from behind glass.

*"There are a lot more different aspects of who I really am. I am not HIV, I am not AIDS. I am a person who has many many life experiences, and all of those life experiences and all of those talents and desires - is who I am. But most people don't know that [because] most people haven't experienced that with me, not the people who are in my life now. Most of them know me as an AIDS activist and AIDS educator, yet that has only been a small part of my life. AIDS is a very important part of my life right now, and something that directs all of my activities, and I am very proud of doing the work that I have been fortunate to be able to do - but that's not who I am"* [F.H., p 6].

And for clients who are not doing as well medically and have started into yet another health decline, all this talk about positive thinking and health activism can be tiring and produce feelings of failure. It is exhausting to have to keep up the image of a survivor when one no longer feels that way. Friends seem fine when a positive attitude is apparent, but sometimes get uncomfortable when the person is truly sick and weak. One client, who is a busy activist, told me that he felt so bad realizing death was near, because it would disappoint so many of his friends that he hadn't been able to beat it.

I find I frequently have to remind clients like him that dying is not failing, that not everyone gets to stay healthy, and that it really is normal to be sick once in a while without having to feel guilty about it. With HIV it is easy to appear attractive and healthy even while the body is being consumed by various infections, and so clients sometimes are accused of exaggerating complaints or using tiredness as an excuse.

One client described the not-well-but-not-sick feeling as being like forever treading water- "You know how when you get sick? Well, with me "being sick" is never "over"; the best I can hope for is that it's just not getting any worse - I don't think I'll ever feel fine again. No, I'm not sick, but neither am I ever well... I'm just always very very tired" [B.R.; private communication].

For both those infected and affected by HIV, grief and anger and desolate feelings must often be put somewhat "on hold", because the politically correct image currently in vogue is that of

"survivor", rather than "victim", so one must be strong, keep a positive image foregrounded (which, as mentioned earlier, is often ironically seen by others as 'denial'), and not allow thoughts of dying into the picture of self that is communicated.

This 'survivor' image that keeps death further at bay makes it even more difficult for loved ones to breach that barrier into the more raw layers of painful emotions and fears, as the person often feels inappropriate (or not socially correct) when dwelling upon these thoughts. So loved ones are at a loss - and their own trauma and feelings frequently kept secret, a conspiracy of silence that is sometimes so deeply hidden in the unconscious as to be practically inaccessible. Political correctness sometimes overrides unmentionable thoughts. And so therapy with loved ones of the HIV-positive client also becomes complex.

Many people who go home to tell their families that they have tested HIVpositive must also at the same time explain how they got that way - and for people who have not explained their sexuality, drug use, or other risky behaviors, this is a big topic to cover in one visit. Sometimes families do reject the person and make it clear they are no longer welcome, and other times there is a surprisingly supportive reaction (often with clients most fearful that love would be terminated or left conditional).

*"I think the hardest aspect for me to deal with in the beginning was dealing with my family. I had this vision in my own mind about what my relationship was with my family. I knew the hardest thing for me to do was to go home and tell my mother that I was HIV-positive. It's the same thing as going to your parents and telling them that you are going to be dying of AIDS - it's one and the same thing in everybody's mind... I knew how she was going to react, and there was a part of me that said, 'I don't want to be the cause of my mother's grief. I love my mother and I know my mother loves me. Why do I need to go home and tell her that her favorite son is going to die of AIDS?' She broke down and cried like I've never seen her cry before. Then she gave me a hug, and said, 'I love you and I've always loved you, and I always will...' I had never ever seen my family react like that before - I was not prepared for that. That was a very powerful emotional experience for me"* [F.H., p. 8].

But families and friends are also human, and sometimes their fear or exhaustion hits a limit in the caring they are able to provide. Clients who are ill expect to be taken care of, and issues can arise when caregivers can give no more. One woman who went home to die found her parents lovingly supportive - until she surprisingly improved, and found her welcome quickly chilled. There is often need to grieve the breaking of trusted assumptions that those who promise to always be there sometimes, in the end, simply cannot be.

*"Recently I realized that... I have reached out to my family [but] they did not return that. They did not pick up the telephone to give me a phone call, to see how I was doing. I had been living*

with this image in my mind that I had a close relationship with my family, and that they supported me. And when I came to the realization that they did not support me - not because they didn't say they loved me, but because they didn't follow through with their actions - this was a very big shock, and I have only recently discovered it. I'm still going through the grieving of this. In my culture, family is almost everything" [F.H., p. 8-9].

#### **Counseling needs, issues, and techniques**

*Very little of what is happening [in the early years] is what the virus is doing to the body at that time. You have to deal with emotional and mental issues as well as social issues... [Although] my culture and traditions gave me courage to deal with issues in my life... there are times when I am just going along doing my business, walking down the street... and all of a sudden, out of me comes all of these emotions" [F.H., p. 3].*

Offering psychotherapy to people living with HIV is a complex task, and it is extremely important to not perceive a problem until the client defines it as such. Good therapy involves co-constructing the mental reality that both client and therapist are participating in, and since it's the client whose needs are being addressed, it is very important to take cues from that person's understanding and explanation of what is happening to them, how they make sense of it all, how they are coping with various big and small losses, and hearing each story without judgement or external expectations.

*"I knew that I couldn't change being HIV-positive, no matter how much as I wanted to. But what I could change about my situation, was the way that I was to deal with it" [F.H., p. 3].*

Listening intently, reflecting back to be sure there is understanding, acknowledging feelings and trying to explore them to know them better, keeping hope without being condescending, respecting the right to choose one's own path and have it change as needed, and other such attitudes are goals that I think important not just for the client, but also for the therapist. My HIV-positive clients have taught me a lot and deeply affected the way that I try to help them.

*"1995 was a time of grieving for me, trying to put the pieces together after losing two of the most important people in my life [my lover and my best friend]. In September, my Mom was diagnosed with cancer...She died at the beginning of February [1996], and I was there with her at the end...It was an agonizing and painful death...The shock of what I had seen lasted two weeks, and when I finally started to feel again, all there was was an empty black hole. I was very frightened. I hadn't been able to grieve my Mother's death and I felt a large part of me had died with her.*

*"I knew I was in trouble and called on my therapist again, as I had after my lover's and ex's deaths. She allowed me the safety to express all I was feeling. There was just a huge hole in my*

*heart. I no longer felt [anything], and I was terrified to look into it for fear it would swallow me and I would lose sanity. She listened very well, repeating what I had said back to me to be sure she understood what I was saying, and then the probing would start.*

*"She has a way of questioning me that makes me look at the situation in a different light, or from a different angle. By urging me gently in certain directions, she brings up aspects of the pain I am in, allowing me to come to an understanding of the multitude of issues that are at work here.*

*The uselessness, emptiness, confusion, the lack of strength I felt to continue, and how overwhelmed I am at grief and dying for family and friends, and for myself. The validation of the normalcy of my emotional state is one of the best things I get out of it [counseling]; the other is that as we explore all the issues I realize that taken one by one, I can deal with them. Like separating the trees from the forest, I am able to see far clearer.*

*"She does not do the work for me - she brings issues to light and from there the ball is in my hands. Another wonderful aspect is that as I am making progress, I can report back to her on my growth, and we can talk of the insights I've gained, of the stronger, wiser person I've become, and the implications these have on the rest of my life.*

*"I know I am a strong and courageous person, a 'survivor' if you will, but there are times I need help handling my life and its obstacles, and there are times when I act from the heart and end up overwhelmed and a bit lost. I really don't know where I would be today were it not for the help and safety that she has offered me in my times of crisis" [J.E., p. 2].*

#### **Issues for Psychologists**

As AIDS is devastating particular groups of people and cultures in something resembling a plague or genocide, it can also easily become a personal issue for those therapists trying their best to help their clients deal with the same thing. No psychologist specializing in HIV psychotherapy remains untouched by multiple deaths in clients or friends.

Despite a lot of new promises regarding treatments, AIDS is a client concern where there is presently very little hope, when even the dreaded word cancer is losing its throathold due to increased survival rates. Clients can survive AIDS, but in reality very few do, and for those who do live a lot longer than expected, survivor guilt is another major issue that arises - as is poverty!

Trying to help clients deal with their own imminent death, and/or the guilt/pleasure of not dying (yet) and still managing to beat very heavy odds, can be a heavy load for any therapist. If that therapist also has not yet dealt with the inevitability of their own death (and how confronting it can actually be very empowering), they are likely not going to be able to help other people clear the

numerous issues around their own. This is a place where transference and countertransference can easily intrude.

If the psychologist has lost friends, family, or lovers to AIDS, they will be wearing their own layers of anger, grief, frustration, and so forth while they try to help others experiencing the related diseases. In this there is not only the danger of personal burnout as the diagnoses increase, but also that in the numbers' multitude, therapists might innocently resort to functional generalizations, categorical labelings, and other consequences of AIDS' increasingly large numbers and thus reduce the client to less than a full complex human in their attempts to treat so many of them.

There are clients dealing with AIDS to try to help, as well as their families, friends, lovers (or those who reject them) to help them communicate with. There are also simple medical consequences such as dementia or incontinence which can threaten the therapist's own limits of tolerance.

Sometimes our own mental stability becomes increasingly overwhelmed by something too complex to encompass therapeutically and/or with medical odds too predictable to keep continually extending our hopes, and our clients', toward the goal of surviving day after day, client after client.

Also there are numerous therapeutic issues clients are trying to deal with, the likes of which I never dealt with in graduate school training; for example, what can I tell a client who finds that people are unwilling to become sexually intimate or even emotionally committed with him because he might die soon (but then again, he may not), or because one tiny error or sloppy sexual practice might result in a possible death sentence?

And then there is one more issue which is not so frequently mentioned in professional discussion about HIV treatment: Psychologists who are themselves HIV-positive or who have arrived at the full diagnosis of AIDS. These are professionals who are quite competent and doing just fine, but for whom the clients' issues are suddenly their own. Transference/countertransference issues are even more complicated when those psychologists in some of the same situations as their clients are actually some of the very best people to be able to help them.

Therapists who are themselves HIV-positive have personal dilemmas that were likely not even conceived of when they were receiving training from instructors who could never have prepared them for some of the choices they must now make about self-disclosure or not (what about duty to inform the client? if the client seems to be AIDS-phobic, should the therapist reveal HIV-positive status?), taking on new clients or not (what if the therapist gets sick and can't work before this client is finished with therapy?), telling colleagues (they say they're comfortable with clients having AIDS, but what about a colleague - does that become more threatening or too close for comfort?), and other more complicated issues which just didn't exist in the days I received my training.

If clients are hospitalized for solely-medical, but not mental, reasons (like drug infusions) is it ethical to continue to see them inside their own hospital room instead of the therapist's office? If they are home-bound, is a home visit acceptable? Can I gently touch a client to offer comfort or communicate caring, without this signaling mothering/smothering/transference issues (or even worse, breaching ethics?). These sorts of boundary dilemmas arise from yet another kind of "closet", one which is inside the emotional house of all of us doing this work, and there are no simple clear answers.

### Conclusion

Sometimes the best thing I can do for my client is to honestly say I do not have answers and cannot give them any advice that will cure them. But healing is my business, and a safe comfortable private space in which to regularly explore what is happening to them is what my therapy tries to provide.

### Recommended Readings

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*Frederick Haineault was a close friend and colleague of Weiser who died of AIDS on December 6, 1995. Co-founder of "Healing Our Spirit B.C. First Nations AIDS Society", he was an AIDS educator who blended traditional Cree teachings with counseling First Nations people about AIDS. His comments included in this paper are from a transcription of a presentation they gave together at an AIDS conference in Prince Rupert, BC in September, 1995 - that they had taped with the intention of jointly authoring this article.*

*"J.E." is the pseudonym requested by a client of Weiser who, when hearing she was writing this article, brought her two pages he decided to write about their counseling journey (that he titled "Why therapy?"), giving her permission to quote from it. He has been living with HIV for more than a decade and wrote this "so that people would understand that looking healthy doesn't mean you don't have problems".*

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