

PSYCHOSOCIAL CONSEQUENCES OF LIVING WITH HIV/AIDS

OR, "WHAT I LEARNED FROM MY CLIENTS AND FRIENDS"

Judy Weiser

This article is dedicated to the memory of Bill Rodda, who lived several years longer than believed possible when first diagnosed, and who taught me firsthand about all those "roller-coaster" parts of living with AIDS.

"And what do you do?" asked my bank teller.

"I'm a therapist," I responded. "I counsel people with AIDS" (never passing up an opportunity to de-stigmatize the word by stating this so matter-of-factly).

"Oh, that's so sad to hear," he replied.

"Not at all," said I, smiling. "It's been some of the most empowering work I've ever done; I've learned far more about living than about dying!"

"Ob!" he exclaimed in surprise. "I thought all those people wanted to kill themselves..."

Rather than beginning with dry statistics, I think it would be more informative to provide some snapshots of a few of my clients to help explain why counselling people living with HIV is more complex than might be expected. Although my private practice caseload is totally HIV/AIDS-oriented, and thus based on many generalizations in terms of presenting issues and treatments, each day is *always* different and each client definitely unique.

N., a long-time HIV-survivor for over 12 years, has now begun health decline. His T-cell count has dropped significantly in the last six months, and various attacks on his body, like shingles and thrush, have begun. Despondent, he told me quietly, "I have to take 21 pills every day, each on different schedules. I have become an observer of my own life, and my free time is no longer my own — it must be monitored. Just once, even just once, I would just like to feel good for one day; *I've forgotten what that feels like*. Last week, when I was so depressed and wanted to call for support on those friends who had often asked me for help in the past, I looked through my address book, but there was no one left alive other than business contacts. I've been deserted; my whole, entire support system is gone. In the

past year, every single one of my close friends has died; my entire gay history is gone; everyone who knew anything about the important parts of my life, the part after I 'came out,' are dead. Now there's no one left to remember me, and no one will be at my funeral."

L. is 19; she became HIV-positive through her father, an IV-drug user, repeatedly raping her. She wants to become a teacher, but isn't sure whether to waste her time continuing with University. She wants to know how long she has left to live, and whether she should risk having a child, so there will be someone to remember her and love her in the meantime. She recently phoned to apologize — she was sorry, but her health had improved, and so she didn't call me so often any more. I found it odd to have to reassure her not to feel guilty for feeling better.

H. is in his mid-forties; his partner of more than 20 years died last year. HIV-positive himself, he is also a Buddhist and has a solid quiet understanding and acceptance of what death means to him. He reports that his friends are having a hard time with what they perceive as his not being very upset over his partner's death, and we discuss expectations, and emotional obligations to other people, and how this affects one's own right to live as desired.

R. is in a panic; he has just been told he has PCP pneumonia, and his T-cell count is now below 100. His doctor back home told him he'd likely be dead in six months and he is anguished and despairing. His new doctor told him there are drugs to treat this now, and not to give up hope. His parents don't even know he is gay; how can he prepare them for this? Should he abandon his newly-established independence in the city and go home to die?

T. had PCP 'way back in 1987; it's "old hat" to him that he was supposed to die a few months later. ("The doctors keep making false promises," he reminds me, "I'm keeping count and they've been wrong six times already.") Now HIV-positive for over eleven years, he's just left welfare (which paid for the more than \$1,000 per month for his drugs) to take a job that pays \$30,000 a year. "I got tired of waiting around to die — that took up some of the best years of my life, and now I'm realizing that this could go on for another decade or two." He's had a few awful medical crises, but despite heavy drinking and a bad cigarette habit, he still keeps going. His motto: "I have AIDS, but it doesn't 'have' me!"

P., proud to be Native and two-spirited, is deeply traditional in his spiritual beliefs — and loves going to the bars to dance all night (though he abstains from alcohol). He's so skinny as to look skeletal, has not many T-cells left, and we've had many discussions about death and after. He complains that his doctor wants to do a bunch of medical tests and give him lots of pills to take, which he doesn't want to do. His doctor wants him to go on AZT "before it's too late," and to take other pills as preventive measures. He wants none of this and is

afraid that once he's in hospital, the doctor will win. So... he's not going to the doctor any more.

E. is a grandmother; she became HIV-positive through a blood transfusion during heart surgery nine years ago. Her husband is loving and devoted, but a bit frustrated at her continual AIDS public education activities (not because he's against them, but because they tire her). Her son, who is gay, is also HIV-positive, though his partner isn't. The partner sometimes feels left out of the mother/son conversations, and found himself one day apologizing because he wasn't HIV-positive too.

J. is heterosexual and married, supposedly monogamously, but while at a convention in Las Vegas two years ago, he got very drunk, joined with his pals, and "rented a few ladies" for the evening. His wanted him to use a condom, but since he told her he was certain he was safe, and she assured him she was HIV-negative, and he 'didn't like condoms,' they had unsafe sex. Now he not only feels guilty, but is also terrified, because his doctor thinks he should have the HIV test because of numerous recent medical problems. "How can I tell my wife?" he asks. And, ethically, what do I do, having just heard from his wife last week that three months ago she herself had a brief affair that she could never tell him about because he thinks she's faithful? The rule about "duty-to-inform" suddenly takes on new urgency and deeper complications....

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B. was very adamant: "It's not so much a fear of death but a fear of dying, getting sick, wasting, and I'm terrified. I saw my friend lying in his hospital bed, wasting away, full of

tubes and under a sheet looking thin; I left the room and sobbed. I know I don't want people to see me like that, and I know that when it becomes my time, I will shut people out so they won't see me and so they won't be so hurt. That way they will remember me healthy. Yes, it will be lonely, but I can't stand seeing sadness in their eyes and not being able to make it better." B. has now died; he did what he planned, and his friends now tell me of their deep hurt at being cut out of his life, each wondering what it was that they "did" to him that made him abandon their friendship in his final months.

M. and A. are both "long-term survivors" (actually more than 5% of all people living with HIV are too, though not written about as often as "victims"). Both have been HIV-positive for over a dozen years. M.'s T-cell count has recently dropped below 800; A.'s still hasn't (and he is angry that they won't accept him into the drug trials tests because he'll skew the results — the wrong way!). Their answer for longevity? They say with a wry grin that it's because they're Quebecois!

As you can see from my few snapshot examples, AIDS is no longer specialized to any one group of people (if, indeed, it ever was). AIDS is now everyone's problem, and in one way or another, it now affects the life of every client we treat. Even the doctors agree — during the first five or six years of being HIV-positive, most people's problems are not primarily medical, but psychosocial!

PSYCHOSOCIAL ISSUES

Counselling people in the time of AIDS is not a simple linear process, even for clients who are not HIV-positive. Once finding themselves HIV-positive and dealing with its emotional and psychosocial fallout, it doesn't really matter where they "got it" — through needles, sex, transfusions, or whatever. These sources may make a difference in prevention education studies, or in issues of medical treatment, but when I see these people in my office, they are all facing the same sorts of emotional issues regardless of their source of infection.

An HIV-positive diagnosis is an emotional rape, a violation of a person's innocence, of their guarantee of a future and their right to health. Once diagnosed, HIV always stays in the foreground in everything else the person does and plans and thinks about. It is *always* there; they become eternally vigilant for even the slightest sign of poor health, and *nothing* can replace that loss and turn their life back to what it was like before. Understandably, people frequently experience feelings of helplessness and seemingly-intolerable levels of anxiety. As one client put it, "It's always there just beside my head, riding on my shoulder."

Whether HIV-positive themselves, or being the friend, lover, family member, co-worker, or physician of someone else who is, any clients experiencing the consequences of AIDS-related personal difficulties require those counselling them to be as fluent as possible with the emotional complexities (and potential family issues) that an HIV-positive diagnosis (or the fear of one) can precipitate.

I believe that we must also maintain a thorough understanding about the basic medical and social facts of both the prevention and the progression of HIV/AIDS, and the resulting consequences to the client. Then we can assist the client toward active collaboration with the doctors and various community services. This aims toward a model of life-affirmation and personal empowerment that helps people to direct their own lives, rather than being passive victims with few choices.

Also, if we are seeing clients who are from various traditionally-marginalized groups such as Aboriginal or disabled people, women, gay men, IV-drug users, or street youth, then we could probably use some extra cross-cultural awareness and sensitivity to our own potential prejudicial attitudes or behaviour.

Young people are a particular area of concern, in that anyone under twenty has grown up with AIDS being already an existing problem, a "given" fact of life, a "normal" rather than a new intruding challenge to be conquered. Few of our youth know of life without AIDS, and this can lead to an apathetic attitude of defeat, resignation, and powerlessness in the face of its dangers. "It is difficult... to credit that which we perceive as overwhelming with any sense of immediacy; it is easier to say, 'why bother?'" (Garnhum, 1993). Youth, who already wear a talisman of invincibility against death, seem to be facing the threat of HIV with an attitude of increasing inevitability.

As if all this were not enough, social workers and other helping professionals must also cope not only with issues of multiple loss and compassion fatigue in their clients' lives, but also in their own. Therefore we also need to know how to handle burnout ourselves and to be able to assist fellow professionals such as doctors to find a way to deal with such unceasing pressures.

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Additionally, there are the long-unaddressed psycho-social issues related to social workers or other counsellors who may themselves be HIV-positive, and the type of clients they have selected to treat (transference issues, fears of contamination, continuing to work while ill, peer support, etc.).

Furthermore, for most people living with HIV these days, AIDS is becoming viewed more as a long-term chronic disability (with related consequences such as poverty) instead of a medical crisis or an illness like cancer which has a predictable linear progression — and a chance of

being finished with it. But, unlike remission in cancer, the consequences of AIDS may be delayed, but not overcome.

Moreover, cancer is not contagious, so people aren't usually so fearful. Clients tell me that everyone is pleasant until friendships head toward intimacy, and then fears erupt that are unique to HIV. "Just once I'd like someone to hold me without being scared," one client sighed.

As knowledge about cancer has increased, fairly certain time-lines have developed for death, remission, "safe survival" limits, and so forth. With AIDS, there is no such certain exponential curve — people have been told they will die from AIDS, and this, they have been told, is "certain." But then they are given no time-frame from which to form dependable expectations or make life decisions to guide their personal journey. Should they leave graduate school? Should they take that job that has a two-year contract? Should they

go ahead and get married?

The complication here is that there is no road-map available for becoming one of those long-term survivors, and each person not yet progressing to health-failure differs in the reasons they give to explain their living so long. Unlike many other terminal or long-term chronic illnesses, "having AIDS" doesn't come with any instruction manual about what one should do in order to guarantee surviving. Good clues exist (physical exercise, good nutrition, stress reduction, emotional health, and so forth), but adding them up doesn't automatically predict an arrival at longer life.

Many people who are fit according to the points above still die quickly, or stay very ill a long time, yet many people who smoke a lot, never exercise, have a drinking problem and are psychologically disturbed are still going strong and looking great years after their predicted death date. So AIDS doesn't come with a list of things that — if you do them properly — will help you live longer. My closest friend who died of AIDS four months ago left me his favourite T-shirt, which reads "Eat right, Exercise — Die Anyway!" In many ways, he was right!

If all that people hear is that no matter what they do, or how long they live, they're going to die from AIDS eventually (and a lot younger than they'd hoped), then there's no tacit acknowledgment from the "experts" that survival of AIDS is even possible (even if repositioned into a revised definition as a "long-term-chronically-manageable" illness).

If the experts never seem to recognize or publicly bear witness through their words that living a long time with AIDS is a distinct possibility, and respond only with carefully-worded disclaimers and doubts, then there can be no positive image to aim for, to try to reclaim one's right to hope. All that people living with HIV can do is live the best way they can imagine and hope that something they are doing is right — but no one can tell them *which* things these might be, and this could drive anyone crazy!

Therefore social workers who wish to help HIV-positive clients will probably have a difficult time working toward life goals or emotional health guidelines using traditional psychotherapy approaches, when neither the very people who are surviving the longest, nor their doctors, have any idea themselves what might help prolong their life.

THERAPEUTIC CONCERNS

A social worker for many years, I am now a psychologist and art therapist in private practice, and thus my approach to psychotherapy with HIV-positive clients is often a bit more eclectic than those trained in only one field. I blend many theoretical modalities, including constructivist, phenomenological, existential, feminist theories, with a systemic

and narrative-based approach. From this combination comes one of my most basic operating assumptions: that it is not AIDS itself which is the problem in a psychotherapy situation with an HIV-positive client, but rather what AIDS *means* to that person. If being HIV-positive presents no problem to them emotionally or spiritually, then by default I would not be seeing them as clients coming to me for help with something they are unable to take care of on their own.

Many people living with HIV do not need a therapist or social worker for anything — if nothing is “broken”, then nothing needs “fixing.” This itself can be a puzzle to those who believe that everyone with HIV is made dysfunctional by it! HIV is a virus; AIDS is a medical condition — these facts have neutral valence until someone perceives them to have some consequence and particular meaning.

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Until people tell their own story about HIV in their own words, and thus construct how it all makes sense for them, I cannot possibly know how they feel about it. And AIDS “means” something very different to each client: some are devastated to the point of immobility, while others seem to deal with it so casually that I wonder if it is actually denial I’m witnessing instead of the “positive visualization” that it appears to be.

This underlying theoretical approach leads to a lot of the techniques I use to help the client examine what has happened and how to plan to deal with it (and loved ones’ responses when told). Once I have decided what approach might help with each particular client, what I actually do with them may involve a number of techniques depending on that client’s particular constellation of psychosocial needs and goals. Both Art Therapy (Bryant, 1989; Bussard & Kleinman, 1991; Fenster, 1989; Howie, 1988; Probus, 1988, 1989; Rosner, 1982 & Rosner-David & Sageman, 1987) and PhotoTherapy (Weiser, 1993) techniques have been used with particular success due to their ability to bypass verbal defences and controls, as have various applications of family systems mapping, hypnosis, dream review, music therapy and other expressive techniques.

In beginning to start actually *living* the rest of their lives, rather than just floating along in unexamined existence (as if hundreds of years will elapse before a death from ripe old age), my clients usually begin examining parts of their life they haven’t previously explored in such depth. These include quality of life issues, meaningfulness and purpose, sometimes spiritual issues if relevant, and a whole host of accompanying tasks involving reduction of stress, completion of unfinished business and resolution of leftover issues with family. They

must set attainable goals (especially in case they outlive their self-imposed probable time-limit), enhance self-esteem and empowerment, and achieve an altogether new model of active collaboration as partners with their doctors.

Many believe that all of us must get anger and depression out from our bodies or their effects will batter our immune system, limiting its capacity to fight infection. Tears clear the lymphatic system of chemical by-products of stress and cell damage, and it seems to me that respiratory difficulties are much more common in those clients who are unable to cry easily. Studies of “hardiness” have shown that regular physical expression of emotions is essential for maintaining immune system health, and social workers can help clients become more comfortable with experiencing and expressing their emotions by providing a safe dependable environment in which to do so.

It is important for social workers and other mental health professionals to have as much understanding of the basic medical facts, currently-used treatments, and medical/mental consequences of AIDS as possible. Clients who are frightened need counselling from professionals who can talk factually rather than make things worse through simple ignorance. We need to know what T-cells and their fractions are, what the client’s blood-workup reports mean, and work with the client to ensure that *they* understand these things. It’s the only body they’ve got, and we need to encourage them to take charge of what is done to it. As one client put it, “I suddenly realized that this is not a ‘dress-rehearsal’; this is *it!*”

If we do not understand the differential implications of dementia due to prescription drug disorientation, low haemoglobin, or fluids, with that from lymphoma or toxoplasmosis, then we are less effective at coping when faced with it. When the client comes in with a label such as “hairy leucoplakia,” “MAC,” “shingles,” or “Kaposi’s Sarcoma,” for example, this is not really the time to be uninformed as to whether the condition is terrible (or contagious!) or not.

Now that more promising treatments such as several kinds of “protease inhibitors” or “non-nucleoside reverse transcriptase inhibitors” are being announced as miracle drugs every few months, we must keep pace with our clients as they are faced with decisions that may literally have “life or death” consequences. And, if we do not understand the psychological stressors that accompany all such decisions, we fail our clients through ignorance, which I view as another form of abuse.

Social workers and other counsellors also need to be aware of the political and social aspects of medications and interventions; for example, the debate regarding the safety or efficacy of some anti-retrovirals such as AZT, which is not always the easy answer doctors present it to be, or the fact that some people are dying while several of the drugs already

proven effective in saving them have not yet been governmentally approved for release and use, due to financial or political concerns. More subtle issues may be completely overlooked, such as the complex interface between the transgendered community and those who medically or psychosocially treat them as if they were simply a subset of the gay population, or, as another example, the dilemma of transsexuals receiving long-term hormonal therapy who must also be given conflicting drugs for HIV.

There are political, and occasionally genocidal, racist, or misogynistic, overtones accompanying many of the seemingly-simple treatment issues relating to HIV/AIDS. We ourselves may not be aware of these, but our clients are, and the consequences of the resulting victimhood are psychosocial as well as political!

If we are ignorant of what our clients are talking about and dealing with, we cannot be of much help in assisting them to find their own personal truth and course of action within them. When they repeat casual popular beliefs, such as "HIV always equals AIDS or death," our attempts to get them to understand the deeper personal or interpersonal complexities of such claims will crash into our own attitudes as well as their confident blind trust of public platitudes. And other claims, even those from prevention programs, such as, "Oral sex is safe sex" or, "As long as people are practising safe sex, they don't need to get tested for HIV unless they actually become sick" are not only debatable, but also potentially dangerous. We had better have our facts clear before entering into such discussions.

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And, since it is also true that, for most people living with HIV, one of the other big issues is poverty — just staying alive and healthy while managing to still eat and pay rent — then those of us in private practice also must come to

terms with the extra burden (or guilt!) of charging such people for their psychosocial counselling! For example, those of us counselling Aboriginal street youth are puzzled that government agencies will pay for medical or prevention counselling, but seem to perceive requests for emotional counselling funds as a frill. These sorts of problems affect clients' lives; they also affect our ability to help them.

It is also crucially important that clients (and those counselling them) understand the essential connection between the mind and the body. Psycho-neuro-immunology research has proven numerous times that the ability of the immune system to fight off infections is directly tied to a person's emotional health and attitude. We have a role in assisting clients to enhance their emotional resources and their ability to reduce stress. They must strive to

strengthen their bodies, yes; but they must also learn how to strengthen their minds, in order to harness optimum energy for supporting their own survival. A healthy lifestyle and a positive mental attitude are basically the same thing, and understanding this is a major goal in HIV/AIDS counselling.

Reaching strength in emotional health leads directly to individuals who can be pro-active regarding their health and thus more responsible for what is done (or not done) to their body. In this way, they move from being victims to being active participants in their own life — and improved emotional health usually results from becoming aware that choices do exist.

Yes, there is fear and anguish and the need for deep grieving, expressing rage, and acknowledgment of loss. Death from AIDS is not "nice;" it is usually prolonged, quite the roller-coaster of non-predictability. "If someone close to you is dying, you're led to expect the bittersweet farewell, the supportive family scene, the tender moments of *Terms of Endearment*, and are astonished to find yourself stuck instead in a private screening of *The Exorcist*" (Scott, 1988). But there is also room for a bit of black humour and learning to enjoy the days as they come. Humour gives back power and a measure of control over that which threatens to overwhelm. Counsellors who take AIDS (or themselves) too seriously sometimes have trouble with the black humour that long-time survivors use to keep AIDS at bay: "Humour and romance are more necessary than ever. It's what gets you through. There's no cure for AIDS and there's very little treatment. Sometimes a punchline is the only weapon we have [left]" (Rudnick, 1995).

One person described AIDS as "the guest that won't leave — the one we all hate. But you have to remember — hey, it's still our party" (Della Penna, 1995). A good friend who died last year asked me to put on his panel for the AIDS Memorial Quilt (normally a solemn creation) his motto: "Death the Ultimate Fashion Crisis!". There's a magazine in California produced entirely by people living with AIDS called *Diseased Pariah News* with empowering articles and images direct from persons living with AIDS for each other, and a T-Shirt company in Ohio called "Night Sweats and T-Cells," producing shirt slogans like "Annoy them — Survive!". This does not present as victims waiting to die, but rather empowered people living well in the meantime.

Such black humour may seem maudlin if introduced too soon in a client's process, and some clients are never in the mood for humour about their situation. But for those who have been through many years of the AIDS-maze, such bad jokes and silly stories are a small way to regain a bit of power and revenge — so it helps to be forewarned in case this appears.

A lot of heterosexual people are now finding themselves HIV-positive, and even on this

continent there is a vast increase in the numbers of women sero-converting. The "us/them" boundary separating positive populations from negative has already begun to blur, yet the "coming out" (with AIDS) stigma lingers due to past homophobia and other prejudices. This is a problem not only for clients living with HIV, but also for social workers and other therapists, particularly those who are not "out" about their own HIV-positive situation. Professional counsellors who are themselves living with HIV can be very effective (just as those with other chronic illnesses still do their work effectively). However those who counsel people with problems similar to their own may find transference and counter-transference issues a lot more complicated than usual.

Another thing which is more complex about doing HIV-related therapy is the topic of touching the client, which is usually ethically forbidden — but this taboo may have more flexible boundaries with HIV, because non-sexual hugging or touching takes on new meaning when dealing with people who are sometimes treated (by themselves as well as others) as tainted or untouchable. Hugging or patting a shoulder or knee without invitation is certainly inappropriate, yet such physical communication through touch, *with* permission, can be a very powerful nonverbal signal of acceptance and lack of fear. This is a topic very rarely discussed professionally, and yet one I am certain that many professionals who provide counselling about HIV must deal with frequently as stigma can be a strong barrier to treatment.

THE ABILITY OF THE IMMUNE SYSTEM TO FIGHT OFF INFECTIONS IS DIRECTLY TIED TO A PERSON'S EMOTIONAL HEALTH AND ATTITUDE

No matter how empathic or how knowledgeable the HIV-negative counsellor, no matter how good our intentions or our depth of prior experience, we can never know first-hand what it is *really* like to live with HIV all the time when it never *ever* goes away. It can colour everything people do and it can keep them from living spontaneously in the moment. And this directly affects their ability to respond to psychotherapy designed to help them. No matter how empathic the HIV-negative counsellor might be, there will always be a gulf between HIV-infected and HIV-affected. Even though compassionate caring can bridge that gap effectively, there will never be the same truly personal experiencing of HIV.

The AIDS activist community already knows this and some of the best emotional support offered to HIV-positive people these days is being done by peer counsellors, regardless of their level of formal therapy training. Social workers should be encouraged to support these peer counsellors with better training and emotional support.

I often encourage counselling trainees to be tested anonymously for HIV. No, I *don't* require them to go pick up their results, simply to experience personally what their clients have

gone through — the social stigma of reporting to the clinic and being seen there, the gut-wrenching fear that pervades during the wait for results, the terrible limbo of not knowing, and the slow-motion pause in time while the report of the results are read (regardless of the actual answer).

PRACTICAL SUGGESTIONS

AIDS presents many dilemmas for which most social workers have not been prepared in their training. We sometimes find ourselves uncertain about what exactly *will* best help our clients.

Therefore, in many cases, I have found that experiences with clients and friends have taught me more than formal training. Trying to format a concise framework of practical suggestions for this article has resulted in a list of recommendations of the things I think most important for my clients' emotional health and enhanced empowerment.

1) *Taking more personal responsibility and being more self-directive with regards to their own medical care* — through a partnership model of active collaboration with the personal-care physician and more informed knowledge of medical facts and treatment options. This includes making sure one's own health is as optimal as possible under the circumstances (stress-reduction techniques like yoga, exercise, relaxation, plus vitamins, good nutrition, and so forth), as well as activities focused on providing hope and healing for as long as possible.

2) *Exploring and clearing emotionally-complex issues* — such as exploration of the process of dying and the spiritual meaning of death; for example, responding to a client who told me plaintively, "It's not fair; I'm supposed to grow old; I feel cheated." Life-reviewing tasks can provide affirmation of personal feelings of accomplishment and validate the value of the intangible legacy being left behind. These more positive activities help balance the heavier tasks of grief-completion in self and friends; resolution of unfinished business and/or family-of-origin (or family-of-attachment) issues; attempting to repair or make restitution for past hurtful actions; dealing with one's own slow physical decay and the feelings of anger and powerlessness this produces.

3) *Encountering (and experiencing) negative emotions rather than avoiding or denying such feelings or numbing against them.* When people risk and trust exploring negative emotions such as fear or sadness, they often find a sense of validation that it is all right to have such feelings. With this comes the ability to accept their own and others' feelings better, as well as to be more fluent and comfortable with offering emotional comfort to others.

4) *Developing and strengthening personal coping skills* so that small crises aren't bigger than they need be. These skills permit a more positive perspective to emerge, where AIDS can be perceived as a medical condition rather than an overwhelming totality. They also assist the translation of anger, anxiety, despair, and other negative feelings into more positive outlets and strengths, and (one hopes) there can be some time for enjoying the simple small pleasures of spontaneous daily life. "Living in the moment" becomes richer once one realizes that "now" is really all anyone truly has.

5) *Separating the illness from the person*, so that self-hatred and internalized homophobia do not automatically accompany being HIV-positive. This is what is meant by saying that "a person has AIDS, not the other way around." The illness can thus be externalized into cognitive terms for rational reflection or analysis, so that the self is not psychologically destroyed in solving the medical problems.

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6) *Finding a means of accomplishing financial security*, which is frequently overlooked as one of the biggest problems of living with HIV/AIDS. Poverty is a major concern of many HIV-positive people, and there are numerous emotionally-laden issues surrounding it (such as whether to get food bank deliveries, go on welfare, quit a high-paying job in order to have less stress, and so forth).

7) *Permitting, and being able to ask for, emotional support from others and nurturing a support system* that it is possible to be bluntly honest with. With this comes understanding and acceptance that others have emotional needs too, and that it is not only the HIV-positive person dealing with anger, guilt, grief, and similar feelings. This also connects directly with a more urgent need to resolve issues regarding the possible need for future family support (especially if family members may not be supportive of the client's lifestyle). Also this helps to explore potential dependency issues so that when the time comes for being physically dependent upon others there is not so much psychological baggage carried along.

8) *Becoming more of an activist (at least personally, even if not choosing to do so politically)*. Learning how "bearing witness" to a wrong can help even if you cannot stop the wrong from happening — this can be very empowering for escaping feelings of victimization. AIDS is political, and activism at any level can be helpful just through the educating that occurs. If showing understanding of this is desired, even indirectly, you could indicate support by simple gestures like having such items as activist-oriented books,

magazines, pins, posters, or shirt slogans, in the client's line of sight, as well as being personally familiar with some of the local AIDS service agencies, personnel, and activities.

9) *Finding some method of AIDS-free "down time,"* where AIDS may well be part of one's life but not defining its whole. There must be time for people to be who they are when they aren't being defined by AIDS, when who they are inside themselves is more important than what they do or have. As one man put it, "I can't let my illness define who I am; I have AIDS, but I am much more than AIDS!" Similar to the use of "black humour" as a distancing tool, AIDS-away time helps achieve some external perspective and additional cognitive control through moving the problems to a further distance (like work problems fading during a holiday).

And finally, for friends, families, and caregivers, there is much the same list to explore psychologically, which can be even further complicated by additional emotional issues. There may be survival guilt, multiple loss overload, compassion fatigue and burnout, anticipatory grief — just as in those loved ones living with HIV for whom they are caring. *Not only the client needs AIDS-free time once in a while!* Being a caretaker is sometimes not as easy as expected, and we may be called upon to help those people supporting our client too.

There are implications for us within the above paragraphs — not only in terms of what to do to help our client, but also in understanding that the same list applies to us too. When we are urged to "confirm that the patient's feelings are valid, fears understood, and needs and wishes legitimate and important [as] such confirmation can be a powerful tool for building self-acceptance" (Rosner-David & Sageman, 1987), we might take notice that these are also good instructions for taking care of ourselves, and our ability to continue to provide help. It is not just the clients or their caregivers who must realize that grief is not something to be 'overcome'; rather, it is to be 'gone through' or 'experienced' and if we do not take care of ourselves, we cannot help others.

From all these years of doing this work, one thing has become very clear in my mind. When common characteristics of long-term survivors of HIV are described, they seem to me to be the very same characteristics possessed by long-time-surviving social workers or counsellors of these people! What activates the immune system and enhances emotional health in one person should work just as well for others, and so the above recommendations can also be seen as good directives for us, for avoiding burnout or emotional overload!

My own personal list has emerged after all these years into being a succinct combination of four things necessary for my own emotional survival: believing in my own future and my

right to direct it as I see best; remaining willing to live very intensely and vulnerably and not "shutting down" my feelings; doing what I believe is right and ethical in my actions so that I continue to have choice and control over what I do (as long as I am willing to accept that the resulting consequences are no one's fault but my own!); and finally, remembering that to avoid burnout, I must be willing to take as well as give, to ask for help myself sometimes. Thus I recognize that I, too, have needs and the right to have them acknowledged and fulfilled, and that I do not always need to be the "strong knowing one" in a relationship. I think this list serves me well, and many of my clients have found it a good credo too.

CONCLUSION

Much as my long-term surviving clients report the chilling feeling of there being no one left alive who will remember or mourn them since everyone else they knew has already died, I have a similar feeling that I have been doing HIV-related counselling work for years, and yet there are very few people alive out there who can remember (or remind me about) whatever help I've given.

Colleagues working in fields other than AIDS somehow just don't fully understand the depth to which those of us who do are affected by the continual multiple losses and accompanying compassion fatigue — but neither do they fully comprehend the "flip side" of it all, those beautiful (and sometimes crazily funny) intensities in which I find myself living fully, daily, as a consequence of knowing clients and friends who have taught me that every day might also be my own last one — therefore I should live it, and feel it, fully.

Knowing people who are living with AIDS has brought me a heightened awareness of the treasure and fragility of life itself. I work all day with people who know they may not be here the next, and this has re-framed my own life into a different approach of not leaving business unfinished or emotions unexpressed. I have lived a more vitally intense existence. And this brings me freedom and joy, much the same as my clients report experiencing when finally seizing their own lives for themselves, no matter how little time they think they have left.

We must remember, and help our clients remember, "Dying isn't failing. [No matter who you are] you're going to die some day. If you... do things to avoid death, you're going to feel like a failure in the end. If you do things so that you can enjoy your life to the fullest, the by-product will be a healthy immune system and a longer, happier life" (Siegel, 1995). This, then, is why I stay in the work and keep making new friends and taking new clients even while knowing that many of them might test HIV-positive or die some day. One of my inner pleasures of doing therapy well is to see my client improve in emotional health, which is still possible with AIDS, even if their physical health is failing. I like to think that, even if I cannot "cure" them, at least I can try to help them "heal."

Note:

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EDITORIAL POLICY	2
EDITORIAL	5
LIST OF READERS	6
LETTERS	7
AD HOC HIV/AIDS COMMITTEE OF CASW	8
CONFIDENTIALITY VERSUS THE DUTY TO PROTECT: AN ETHICAL DILEMMA WITH HIV/AIDS CLIENTS <i>Sharon Taylor, Keith Brownlee, Kim Mauro-Hopkins</i>	9
PSYCHOSOCIAL CONSEQUENCES OF LIVING WITH HIV/AIDS: OR, "WHAT I LEARNED FROM MY CLIENTS AND FRIENDS" <i>Judy Weiser</i>	18
DEVELOPING THE ROLE OF A SOCIAL WORKER WITHIN A MULTIDISCIPLINARY TEAM IN AN HIV/AIDS OUTPATIENT CLINIC <i>Judy Lifshitz</i>	34
WALKING WITH PEOPLE: RECEPTIVITY TO LEADING AND BEING LED <i>Bobbie Boland, Helen Murphy, Frances Ennis</i>	43
HIV/AIDS AND MULTICULTURALISM: SHARING RESPONSIBILITIES AND RESOURCES <i>Cbeb Cho</i>	49
CHILDREN BORN TO MOTHERS WITH HIV/AIDS: PSYCHOSOCIAL ISSUES OF FAMILIES IN CANADA LIVING WITH HIV/AIDS — A PRELIMINARY REPORT <i>R. Salter Goldie, D. DeMatteo, S.M. King, L.M. Wells, G. Aykroyd, C. Bennett, M. Brownlow, F. Doutrelpont, C. Harrison, K. Ingebrigtsen, W. Miller, B. Modrovsky, L. Montambault, B. Pottier, L. Scheckter, B. Snow, R. St. Pierre, D. Stevenson, K. Tataryn, M. Vibien</i>	55
LEADING THE WAY <i>Anette Goldstein, Susan McGowan, Beverley Antle, David Brownstone, Shelane Donoghue, Marjorie James, Gail Sloane, Merewyn Rodger</i>	67
AIDS, SOCIAL WORK, AND THE COMING HOME PHENOMENON <i>John R. Graham, Keith Brownlee, Ian Ritchie</i>	74
SEEKING ENTITLEMENT: SERVICE PROVISION AND THE ACT OF ASKING <i>Shirley Grosser</i>	85
FROM THE PERSPECTIVE OF A PERSON LIVING WITH AIDS <i>David Kelley</i>	101
SOCIAL WORKERS AND HIV PREVENTION: A MODEL FOR PREVENTIVE PRACTICE <i>Lynne Leonard, Steve Hotz</i>	108