Pinning Down the Psychosocial Dimensions of AIDS

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Nurses dramatically affect the experiences people with AIDS have with their illness. To have a consistently positive impact on those experiences, nurses have to care for AIDS clients with an extra measure of understanding, which isn’t always easy to muster. Unfortunately, when the experts discuss the psychosocial problems AIDS creates for clients, they seldom address the psychosocial problems that people who care for clients with AIDS must face. Frequently, the problems AIDS clients encounter—a reaction to the stigma, anger, denial, and isolation, for example—are mirrored in the professionals and para-professionals who work with them.

At Gay Men’s Health Crisis in New York, we work with about 3,600 men, women, and children with AIDS every day, as well as with the families and care partners of those people. We have found that, although our clients experience problems that we do not experience along with them, looking at those we tend to have in common can pave the way for dealing with all of them.

The stigma associated with AIDS is impossible to ignore. There is a sexual connotation, and there is outspoken hostility from individuals who fear homosexuals and who fear drug users. Often, just when our clients have come to grips with having this illness, along comes a gruesome article in one of the tabloid newspapers that talks about putting people with AIDS in isolation camps, and it knocks their stability right out from under them. I work with a support group, and I can usually tell what’s gone on in the media that week the moment I walk in the room. The effect on clients is that dramatic.

Caregivers’ Stigma

What has this to do with nurses? Nurses cannot—just as all of us who care for clients with AIDS cannot—avoid the possibility that, when we work with these people, we may take on a part of the stigma ourselves. If we let it be known in our circle of friends that we’re working with AIDS clients, often we find that friends aren’t calling as much, particularly those friends who have children. Explaining the facts about the illness doesn’t always help. Sometimes, we just have to learn to accept the reaction. Also, it is possible that nurses will feel isolated from colleagues because they are sympathetic to clients with AIDS. Creating waves by disagreeing with the majority opinion in a system that doesn’t take waves easily may increase a provider’s sense of personal isolation.

Anger

AIDS is filled with anger. People with AIDS walk around angry 99 percent of the time. They’re angry at the media; angry at having their careers suddenly pulled out from under them when, often, they were at the high points of those careers; angry at being rejected by friends and family if that’s what they’ve experienced; and angry about having this illness. Anger permeates the loss of control and the loss of independence they experience. Some of that anger is directed at us. And we feel terribly angry ourselves. We feel angry because our clients are angry with us. We feel angry that they’re probably going to die, and angry about the sense of hopelessness and helplessness that creates in us.

Denial

We encounter denial all of the time in our clients. We don’t see them following the progression Elizabeth Kubler-Ross suggests: denial to anger to bargaining to acceptance to death. We see all of those things all of the time in the same person. I think nurses experience that as well. An individual will be in denial one day, then furious the next, then talking as though he or she is in acceptance a week later, then back to anger, then back to denial. We do not consider that destructive—denial is a useful coping mechanism. The only time we interrupt someone’s denial—try to intervene and move him or her to a different point—is if the denial is causing him to act in a way that is not good for his treatment. For instance, if someone says “I don’t have this and I’m okay and I don’t have to go to a physician or take my medication,” then his denial is harmful.

We also go through our own denial. There are times that we work with someone, and we’re certain this time it’s going to be different. More commonly, our denial will cause us to say “he’s really not that sick; he could get out of bed and do things for himself if he really wanted to.” Chances are, he cannot. We frequently hear from our clients that their friends, their families, and their health care providers say, “You could be doing more.” They feel that they cannot do more, but our own denial steps in to try to persuade them not to give into those feelings. It’s too painful for us to watch it and to accept it. Our denial and theirs creates conflicts.

Isolation

People with AIDS feel tremendously isolated. Sometimes what they feel is not real—sometimes they have isolated themselves because of their difficulties dealing with their own feelings about AIDS. But often it is very real. One of our primary roles at GMHC is to reduce this isolation. Many of these people have been very active, very involved, and have had very large networks of friends and colleagues. Then they find they are no longer able to be active—they cannot work, there are not as many people around them as there once were.

We, too, feel isolated. Many caregivers are very good at nurturing people and very bad at obtaining support for ourselves. When people ask us if they can do anything for us, we say “No. I’m the caretaker; I’m the nur-
A Client’s Perspective

Joseph, the speaker in this piece, participated in a panel discussion with Ms. Puri at the AIDS workshop. Last January, Joseph has allowed us to share some of his thoughts in order to give our readers insight into how AIDS affects the people who have it.

"I have AIDS. I've had AIDS for seven months now, and I'd like to tell you how I feel and how I've responded to the care I've received.

When I had to go into the hospital with pneumocystis carinii pneumonia, it was the first time I had ever been in a hospital, and I was very nervous about it. There was a sign on my door that said, 'Blood Precaution,' and many of the patients who came into my room wore gloves and gowns. I made a fool of myself; it was impossible to feel at ease. I was anxious, and I was afraid I was going to die. I tried to watch someone throw away perfectly good plates and silverware just because I had eaten from them. After that, I let the food outside my door until someone transferred it to paper plates. Usually, at the time someone brought it in, it wasn't really edible.

It was a nurse who always stopped in and asked me how I was doing and if I needed anything before he started his shift. Although his visits were brief, they really made me feel better. Since my terminal illness, he has come in two or three times a day. He always asks how I am, and he brings me things to eat that I would never eat otherwise. He has really taken away some of our turer," and we end up feeling isolated when actually we’ve neglected to reach out for help, or we’ve pushed it away.

Loss

AIDS is a series of losses—loss of health, loss of friends or loved ones, and loss of job, home, economic independence, and the ability to carry out day-to-day tasks. We try hard to help these people regain control—to avoid infantilizing them, to avoid being overnurturing, even when we want to be. We try to keep their feeling of independence intact as much as possible.

At the same time, we feel out of control ourselves. We cannot control AIDS, and that makes us feel helpless and hopeless.

Having considered some of the psychosocial problems we confront as we care for clients with AIDS, the next question is "What can we do to help them?" There is much nurses can do to help. Our new volunteers often ask us to help in one hospital compares to the care in others. Our response is always the same—it depends on which floor the client is on and on which shift on which floor you have to relate to. In our informal grapevine, we have the hospital floors in this city pegged. We know which floor in which hospital you would want to be on if you had to be admitted with AIDS. People do not often choose a physician based on the quality of the nursing care at the hospital with which he or she is affiliated. Our clients do.

Nursing care—the hands-on care as well as the availability of it and the caring with which it is given—has a dramatic impact on our clients. No one expects us to make people with AIDS better. But one important thing we can make above and beyond trying to make them physically comfortable is to be available as listeners. Frequently, those closest to people with AIDS won’t let them talk about the way they feel. As soon as a person says, "I’m afraid I’m going to die," the friend, family members, or lover, says, "Don’t talk like that; if you don’t talk that way, it won’t happen." Loved ones often refuse to discuss it because they cannot tolerate the way it makes them feel. So, if we are just there for these clients, listening to them, we are giving them some very important help that they are probably not getting elsewhere.

We all have a challenge in trying to work out how we can bear with a situation that is so difficult and so demanding and still give people the kind of care they need to keep their quality of life as high as possible. It’s frustrating, and it’s painful. One way I think it’s possible to help is to clarify our personal feelings about AIDS. If we disapprove of our clients’ lifestyles, it will come out in the quality of our care. People are entitled to feel the way they do, but we should recognize how we feel and we should work on it if we’re going to work with people with AIDS.

We need support to do that. Unfortunately, none of our professions takes into account the grieving process for caregivers. We work with a client for a long time, we develop a relationship, but nobody talks about how we deal with it when he or she dies. How are we supposed to process our feelings about dealing with a population that has a very high mortality rate, that are probably in our age group, and that we get very close to? We have to look for support within our workplaces, whether that support involves formal or informal groups. It is not possible to do this work for any extended period of time without being able to work out how we feel about it. The way to cope is not to withdraw our feelings, because then we lose our empathy. The trick is to try to find a balance—and it’s a difficult one—that allows us to keep working at the kind of quality level we want to without burning out ourselves.