

Caring for the Whole Person with HIV: Mind, Body, and Spirit

The Very Reverend Father Drew A Kovach, MD, MDiv, ABFM

Introduction

When we care for our patients, we care for whole people. We strive for levels of healing that result in life being livable, not just being alive. When I first started the practice of medicine in 1973, what I wanted for my patients was good life. In caring for the HIV patients we want good health and good numbers, but more than that: we want them to have a good life.

HIV/AIDS—I finally can now call it a chronic disease—impacts every aspect of a person’s life: social, economic, physical, emotional, and even spiritual. For this reason I take a holistic approach, the mind-body-spirit approach. I call it the trinity of man, three spheres intersecting with each another. In the days before Highly Active Antiretroviral Therapy (HAART), my patients with a balance of mind, body, and spirit did better than others. In the HAART era, disease, distress, pain in any one of these spheres always impacts the other two. And today, with medications to control the HIV virus, clinicians need to continue to manage whole people to make people whole, not just treat the numbers or the lab values.

I talk with my patients about the length of life, but I much prefer to talk with them about the depth of life. Life is both too long and too short to be miserable.

We can’t just treat the mind and the body and ignore the spirit. We need to assess the patient and ourselves. We need to meet people on the road where they are, not where we think they should be.

Living with HIV Chronic Pain

Frequently the HIV patient is in pain—even when they are otherwise doing well and the virus is under control. We need to add another dimension to our care because the pain is real and the pain needs to be treated. We must know how to manage chronic pain.

Financial Issues

“I used to be able to work, but then I got sick; then the meds came out and I got better and I feel I could go back to work. But if I go back to work I’ll lose my social security. And in the infinite wisdom of our government, I might not get it back. What do I do?” My patients are in great angst about that.

Job Issues

When you go to a cocktail party, what’s the first question people ask you? “What do you do in life?” If you say “I’m disabled and have AIDS,” they may well back away and they may go talk to someone else. What do you do? So much of who we are

is what we do. “What do you do in life?” How are they going to respond to that question? How is it going to make them feel? A feeling of self worth; a feeling of pulling your own weight—our work is very important to us because it gives us identity. It gives us connections with other people. Work is very important because it creates an identity: a feeling of self worth, a feeling of pulling one’s own weight. It creates connections with others. When asked, “What do you do in life?” if the answer is “I’m disabled. I have AIDS” the reaction is never certain: it can be horror, fear, or acceptance.

What about visiting the physician? What if all the papers under the refrigerator magnets have to do with medical care? That’s not good, is it? How many reminders are needed to remind yourself of a chronic illness? In my clinic, we have tried to make it “one-stop shopping” where a patient could see a number of clinicians and receive treatment during a single appointment.

Emotional Issues

What about the emotional issues of HIV? There is a difference between heartache and chest pain. Heartache can cause chest pain and vice versa. There’s a difference between mechanical low back pain and who’s on your back—your

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boss, your partner, husband, wife or anyone else for that matter. There's a difference between being worn out and having clinical fatigue. Having HIV can wear people down. It's a heavy burden to carry. It's all about how people live with this chronic disease for a lifetime.

Emotional issues commonly are centered around relationship issues. Jesus said "Love God, love your neighbor, and love yourself." In all my years, I haven't found too many people who love themselves very much. That's too bad because unless you love yourself, how can you love anyone else?

Partner Issues

Think of it—past, present, and future. A patient may think: "I used to have a partner but he died. Who will love me now? Am I ever going to have someone in my life? Will I ever have someone to love and who will love me?" In another situation, one partner may be positive; the other negative—we call them a discordant couple. Just think of what HIV/AIDS does to the emotional dynamics of that relationship. One now becomes the caregiver and one becomes the care receiver. What about when both are positive? At any given time, one partner's T-cell (CD4) count is going to be a little bit higher even though they may both be doing well. It can be a wedge in the relationship at times. What about the situation of a patient who has no partner? Now, I'm all for the birds, the plants, and the fish in the apartment when you come home, but it's still an empty apartment. And how sad is that? We need the touch of another human being in our lives. And then outside of partner relationships, what about family and parents? Has the patient told them his or her status? Who do they tell? When do they tell? I

remember the bad old days when the young gay man is lying dying in the hospital and the parents come in not knowing he's gay let alone dying from AIDS and, as his physician, I have to give them both pieces of news. I remember one family simply running out of the room and the patient died with only me and the nurse in the room. What about HIV patients telling friends and coworkers? Again, do they tell them or not? Who can they trust? How much of a secret is it? How many times do they want to tell their story? And when they do, do people treat them differently? Do they judge them?

Anxiety and Depression

I call them "the twins." They're never separate. In 34 years of medicine, I've never seen anybody 100% depressed and 0% anxious or 100% anxious and 0% depressed—I don't think I've ever found anyone on the 50/50 line either. It's a continuum with overlapping symptoms and we need to treat them accordingly. My feeling is that every single individual living with HIV disease will become clinically depressed at some stage—early, middle, or late. This disease grinds people down. I challenge my colleagues in other areas of medicine to treat people's depression. They're going to get better and they're going to have better quality of life regardless of their pathology. Depression is a thief in the night of quality of life, and the physician needs to know it and the patient needs to know it. So do something! These people are suffering. It's a painful situation. If we really believe in the good life model, we need to use anti-anxiety agents, antidepressants, and, if we do not want to do the counseling ourselves, we need to send the patient to individual or group psychotherapy.

Spiritual Issues

I think when we talk about such things we first need to decide what spirituality is. It isn't religion. I have been a priest and have been involved in organized religion for over 30 years. Religion in my mind is the vehicle to get you to things spiritual. I happen to drive a certain kind of car; you may drive a very different kind of car: but if we're driving the same direction, we will approach the same place. Think of it in terms of God or the creator or whoever that is for you as the hub of a bicycle wheel and we each are on a different spoke. As we get closer to the center, we get closer to each other. It's very simple. We need to be moving in the same direction and we need each other's help along the way.

I often ask patients, "Do you ever think there might be something beyond yourself?" When defining things spiritual these questions are sometimes helpful. Do you think you might be connected some way with others who have either gone before you or come behind you? What about humility? What about something beyond ourselves? Is it the answer to all questions or is it the question to all answers? Is it vulnerability? Is it some kind cumulative wisdom of energy and nature? Is it vitality? Is it so personal in definition, you can't describe it? Is it justice? Is it what gives life? Is it meaning? Is it something so simple as shelter and water and warmth, food maybe? Is it grace? Is it the intersection of meaning and love? I kind of like that one. Is it power? Is it where we fit? Is it purpose? Is it who I am? Is it why I am? Is it unique? Is it inherent? Is it the boundary surrounding the illusion of control? We're all into control and we get really, really scared when that control is taken

away. Is it frightening? Is it taking a deep breath? Is it inspiration in both of its definitions? Is it some kind of confidence that no matter how bad things get, it's going to be okay at some level? Is it filling? Is it fulfilling? Is it fullness of life? Is it fullness of grace? What is it then? I think it's core. I think it's essence. I think it is inspiration in both of its meanings. I think it's life. Soul as in sol; sol as in sun; sun as in light. Where does it come from?

Relationship

My patients have given so much more to me than I've ever been able to give to them. But it is a two-way street. My patients have taught me so much over the years. Medicine is ministry and ministry is medicine when you get down to it. But it can come from the provider; it can come from parents and spouses; it can come from families; it can come from the community of faith, which we call churches and synagogues and mosques. It can come from God or the creator if that is your belief. I think it is purpose of life. I think it is something beyond ourselves.

What about guilt and judgment? We in the church business have

been handing that out in great quantities for centuries. We're getting better, albeit ever so slowly. What about this redemptive suffering business? Is pain the fuel for the journey? Consider it. It comes down to our relationship with ourselves and our spiritual relationship with whomever or whatever that is for you—the creator or some outside force. How do we deal with guilt about lifestyle choices? How do we support gay/lesbian and transgender people, especially in churches? When conflicted, the last thing these people want to do is talk to a religious person. Why? They're afraid of the judgment they'll receive. What about the guilt and judgment patients feel about having HIV? It's been there since the very beginning and it continues to this day. What about feeling a sense of condemnation? Why did this happen to me? What did I do to make this happen? What about hopelessness and helplessness? What about feeling worthless? What about feeling sad? What about feeling bad? What do we do? Again, treat, refer, but for heaven's sake, do something. These people are suffering.

All of HIV has to be managed:

the spiritual, the emotional, and the physical. Making people whole requires a holistic approach. Wellness to wholeness to holiness, it's all on a continuum. Managing whole people to make people whole is what we are called to do.

In conclusion, a few words about my personal journey: 34 years in medicine; 30 years in ministry; 26 years of taking care of people with HIV/AIDS: mind, body, and spirit. Years spent developing the serenity, courage, wisdom, faith, and love that I needed to replace fear, despair, and depression at having so many of my patients suffer and die. There is blessing in all things. It just depends on where we look. This disease provided me a different way to relate to myself and to others. It gave me a different way to look at life and look at death. Death is not the extinguishing of the light; it's blowing out the candle because the dawn has come. Live right now. Love right now. Now is all we have. But now is forever. ❖

Excerpts from Dr Kovach's presentation at the 2007 National Kaiser Permanente HIV Conference in Napa, CA.

Depression is a thief in the night of quality of life ...

Heal the Whole

The reason why many diseases are unknown to the Greek physicians is because they are ignorant of the whole, to which attention ought to be paid, for the part can never be well unless the whole is well.

— Plato, 427-347 BC, *Classical Greek philosopher*