Human Connection

The founder of the Shanti Project reflects on 50 years of service.

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One of the first organizations in California in the 1980s serving people living with HIV and AIDS wasn’t founded as an AIDS agency at all.

In 1974, psychologist Charles Garfield, PhD, founded the Shanti Project in San Francisco as a volunteer-driven resource for people facing terminal illness. Garfield had developed the Shanti model, which taught volunteers “compassionate presence” and “active listening” so that they could provide nonjudgmental support for cancer patients.

The Shanti Project in San Francisco turned its attention to people dying of AIDS in the early 1980s,

and the Los Angeles Shanti Foundation was founded soon thereafter. Both agencies trained thousands of volunteers to simply be with people living with HIV and AIDS, listening to their fears and providing compassionate support during life’s final chapter. Clients came and went quickly, often falling to the disease within days or weeks.

Today, Garfield has a legacy of community service and several books to his credit. Although the Los Angeles organization closed its doors years ago, the Shanti Project is still open and maintains its core mission to provide “human connections to reduce isolation, enhance health and well-being and improve quality of life.”

This year, the Shanti Project celebrates its 50-year milestone of community service. At a recent special event, POZ contributing writer Mark S. King, one of the original staffers at the Los Angeles Shanti Foundation, interviewed Garfield. The following has been edited for length and clarity.

You began your career as a mathematician and worked on the NASA team that sent Apollo 11 to the moon. You are literally a rocket scientist.

Yes.

Your biography says that you didn't find it satisfying. Sir, you sent a rocket to the moon.

What wasn't satisfying was when it was all over, there was nothing to replace it. There was no mission that was worth all the time and energy that we poured into the moon landing project.

At the University of California San Francisco's Cancer Research Institute, you were one of the first doctors responsible for the emotional well-being of cancer patients. And in doing that, you discovered that all the other psychologists were overwhelmed, and you started wondering why you couldn't train laypeople to provide the same services. You must have gotten a lot of raised eyebrows from the professionals.

Yes, there were a few raised eyebrows. But I had the hunch that if you selected people well and if you trained them well, they could do this work as well as anybody. And it worked. The idea was viable. Now, it's 50 years later. I started Shanti when I was 29 years old. Now I'm 79 years old. And we're still here.

Shanti as an organization began in 1974. That was a decade before the AIDS crisis in San Francisco. Tell me about the transition to helping people who were dying of AIDS.

I started getting calls from my medical colleagues and physicians saying, "We have people with a kind of cancer. And it's hitting mostly gay men. Are you available to take care of these folks?"

I held a meeting of the volunteers and the staff and said, "What do you think of the idea of us taking on this new challenge? And by the way, we don't know how the disease is spread." When we made that transition from cancer work to AIDS, almost nobody left. It was just common sense. We stepped up.

There’s a lot that comes with a patient population made up of primarily gay men. Was there any culture shock on your part?

There was a lot we had to learn. We got together four or five people with this new disease, and we asked questions, and we let them tell us what we needed to know. Turned the patients into teachers.

I want to tell you a little bit about my experience with the Shanti model and taking the training in 1986. It was very intense, especially for someone living with HIV, which many volunteers were. But it got me out of my head. I was able to develop empathy for other people as opposed to being caught up in my own diagnosis.

My oldest friend, Lesley, was the first to die in my circle. I remember I kept trying to fix it. My attitude was, “Just tell me what to do because I need to feel as if I’m helpful.” It was about me. It wasn’t about him. Shanti turned that around so that I could just shut up and listen to Lesley.

You don’t fix people. You fix refrigerators.

Are you afraid to die? Does the work that you do make you more comfortable with the dying process?

God, I wish I could say to you, “No, I’ve solved it.” What did I learn from all of that, that might allow me some comfort in considering my own death? What I’m most afraid of is that I won’t use my potential. Am I afraid of dying myself? Me, personally? Probably. But I don’t think about it that much. But be cautious when somebody says to you, “I’m not afraid of dying.” It usually means it’s not yet real for them.

During Shanti’s work with people living with AIDS in the ’80s, spiritual leaders, like Marianne Williamson and Louise Hay, also emerged. They were very metaphysical, and they sort of became gurus within the HIV arena. Shanti never went there. Do you see a difference between what you were doing and what they were doing?

Yes. I’m much more interested in you finding your own strength and your own power than I am being the source of it for you.

The most powerful spiritual experiences I ever had were sitting at the bedside of people who were up against it, whether dying imminently or later, and holding their hand and talking. It’s the two of us who are in this together, and we’ll do the best we can.

And it’s not that somebody’s a guru or a spiritual leader of some great merit. I’m not going to say anything about the people you mentioned. I’m sure they did useful work for people, but they were held in such high regard, as if there are people “up here,” and then there’s the rest of us. And I never saw it that way. Some of the greatest teachers I ever had were patients.

Where would you like to see Shanti in another 50 years?

I would love to believe that in 50 years we will learn much more about empathy and compassion and what it really means to care for one another.

I don’t see some magical transformation over a 50-year period. I do think we’re going to learn a lot more about what it really means to love somebody.

That need is universal, right?

I can’t think of a more barren life than one that doesn’t include some substantial amount of caring for other people. It’s a lot more important than making a lot of money or having a lot of esteem.

Well, if it’s a barren life not to have helped somebody else, then you are living in a garden, my friend. And we thank you.

My pleasure.
