Interview with Kiran Belani
Interviewed by Jennifer Benson
Interviewed on April 4, 1995, Minneapolis, Minnesota

JB: I'll just start, and feel free to ask any questions as we go along. The first thing to ask is how do other people describe you?

KB: [laughter] That's the toughest question, the first one. Well, I think I'm easy to talk to, compassionate, and very . . . What do you call it? I accept all cultures--what would you call it?

JB: I can't think of the word myself, either, but I know what you're talking about.

KB: I think people of color feel comfortable with me. Let's put it that way.

JB: Okay. When did you first become aware of AIDS?


JB: What did it mean to you then? What did you think about it?

KB: Actually, at that time it was just a medical curiosity. 

JB: Okay, so . . .

KB: It was not known what causes it, what was the [unclear] agent, etc. So, I mean, we never thought we'd be seeing it in children.

JB: Okay, yes. And what does AIDS mean to you now?

KB: Now it means--not just a disease, for sure. I've learned that it's not just a medical disease, it's almost like a life situation. I think that's the best way to describe it. More like a crisis situation in people's lives. Oftentimes these people have multiple crisis situations.

JB: What kind of crisis situations do you see?
KB: Lately we've had deaths of moms, mothers dying. Recently we've got news that the mother of one of the children died. That's three times this year now. So that's deaths of young moms with young children. That's very, very difficult. And of course, other crises. Drug use we don't see as much, but we've had three moms in the last two years. Two of them are in jail, one of them is in rehab. Back and forth. So that's another crisis. Then we've had—I can give you examples of things we've seen in our practice.

There's alcoholism, one mom relapsing with the alcoholism, two moms still in jail. And one of the other things we've seen that is a crisis is losing jobs. In the past we saw one or two parents [lose jobs], but lately we haven't seen that.

JB: Is that because of the AIDS?

KB: Also because the mothers have been going on welfare once they find out. Many of the moms that we've had lately have never worked. So different kinds of people, you know.

JB: Right.

KB: The other thing we've seen is pregnancy. We had one mother who became pregnant in spite of having contraception so that she's right now facing a crisis of what to do. So a normal life situation like pregnancy becomes a crisis situation when you have AIDS.

What else have we had? We've had fathers' illnesses. We have two children whose fathers are very ill. In fact we've had fathers that have died in the past. Many times these children are not close to those fathers, but like right now we have two children, one whose father is in the hospital. The other is deteriorating. We have crises every few months. So, not only do the kids have to deal with their illness and coming to the doctor, they also have to deal with these situations at home.

JB: What are the ages of the children that you see?

KB: The youngest we have right now in our practice is 15 months old, and the oldest is 13.

JB: Okay. When did you first become aware of the impact that AIDS would have on your life? And was there a defining moment when you . . .

KB: Actually, yes, I think in 1989 or 1990, when I got four or five kids into our practice very soon. You know, we acquired them soon after one another. And then came along the
social baggage and difficulties with the parents. I had to step in not only as a doctor, but as a non-medical [unclear] too, you know.

JB: Yes.

KB: Not only me, my whole team here, my nurse and other staff. In 1990, when I was alone by myself in practice at the University [of Minnesota], we had a few kids, but we were, you know, a lot of doctors taking care of the same [kids]. Out here in private practice, you have to make all the decisions. That's when I felt the impact. And how little was known, you know, with what to do with these kids. There was very little in treatment, and everything was kind of experimental. You cannot pull out a textbook and say, "I'm going to do this set of tests and this set of blood tests and know the answer and start this treatment."

It's the first time I felt lost doing medicine. I have always been quite confident about what to do and how to do it. And you come up with a situation where things are not black and white. Not too many things in medicine are black and white, but at least we make it to be black and white because we have it written in textbooks. But this disease, it's more unclear.

JB: Right. How does AIDS fit into the rest of the commitments in your life?

KB: Actually, I don't consider myself an AIDS doctor. I see myself as a pediatrician and physician of all children, so that's one of the most important things that we stress in our office here—the AIDS children are treated no different than all the kids we see. And the kids we see here are so sick. The AIDS kids are not the only kids that we see that are sick.

We have kids that are terminally ill from other problems, we have kids that have multiple birth defects that are tremendous, that are so consuming in time and energy for their parents and their families. In fact, the AIDS children look quite healthy compared to some of the other kids we have. So it isn't like we walked into taking care of very sick kids after taking care of very healthy kids. We had already had so many very desperately ill, chronically ill children. Many have died, even the non-AIDS children in our practice have died, over the last few years. So we've been through the grief and the loss of these children from other conditions too.
JB: How do you define your faith? And what role does it have?

KB: Actually, my faith has helped me a lot in the medical career. My religion is the Hindu religion. We tend to see most things like this as not under our control, and that helps a lot with a condition like AIDS because you don't get that frustrated and you don't feel that hopeless. You still have that optimism. And also you are able to deal with death easier. I don't know about other religions, but in our religion, because death is seen as a part and parcel of the cycle of life, that part is easier, and I don't feel so angry and frustrated.

JB: Yes, okay.

KB: I think I feel angry and frustrated at the virus but not at the children dying. So that has helped me. Actually, children dying is difficult for everybody to see, but sometimes when you have faith it's easier to deal with it. That's the difference.

JB: Yes. Does anger play a role in your response to AIDS?

KB: Actually, the only time I get angry is at the people who don't know enough about the transmission and the discrimination. I think that it's people that make me angry, not [unclear], because they are so [unclear]. We hear stories about, for instance, one of our families' sons died of AIDS, and they had a health club, and they hadn't come out with the diagnosis until his death, and once he died they lost all their customers and had to close their health club down. And this is in 1994 in Minnesota, which is supposed to be a progressive society. People going to health clubs--it tells you they are, you know, sophisticated and progressive, and that made me very mad.

So I think maybe it's ignorance, maybe it's fear, irrational fear, which seems to be very common today. For everything, you know. It's a culture of fear, I think. And that makes me angry. I would say that really gets me angry. Not too much else. I'm not a very angry person. [laughs]

JB: How do you define your community?

KB: My community? My community here? I don't get the question.
JB: Do you have a community that supports you in your work, who you consider your friends and supporters, people that help you?

KB: I think my staff in the office is very supportive in our work with children. Outside, my physician colleagues who help me take care of these children. As far as this affecting my home life, it really doesn't. As I said, I haven't been doing much outside my professional life. I mean, I give donations, you know, monetary [help]. I've given lectures which is part of my professional life. I have been to my patients' funerals, but we do that with other kids too. But I haven't done any social work, so to speak. I've not been that involved outside my professional sphere.

JB: I don't know if this question is applicable because of what you said before, but why do you stay in this work and how do you sustain your commitment to this kind of work?

KB: As I said, to me really it's just one of the many diseases that we take care of. I don't see how you can get away from dealing with this. It's just part and parcel of our work. I don't go looking, seeking to do this. It came to me because I am an infectious disease doctor.

JB: Right.

KB: And once you accept what your responsibilities are . . .

JB: So treating AIDS is just part of being a doctor to you?

KB: Yes. Right. [unclear]

JB: How do you define happiness? And where do you find it?

KB: Um, happiness. What kind of questions are these? [Laughter]

JB: I think [they're] just trying to understand people's relationships to the AIDS crisis.

KB: I see happiness as being true to myself. Yes, if I feel like I'm cheating on myself, I see that as unhappiness. And if I'm honest with myself and people around me and people who work with me or my family and my career and my profession—I see honesty as happiness. And doing to others as I would want done to myself. If I do that, I am happy.
JB: What is your vision of America? And democracy, and [unclear]?

KB: I think I'm getting quite irritated with some of the things that are going on. I've been here only for seventeen years, and I think in the last few years I've seen more intolerance and a lot of [unclear]. It's almost like other countries now. In fact it's worse, because in other countries if they're intolerant they'll tell you they're intolerant of you. They don't do it subtly or pretend that they're tolerant when actually they're intolerant. But [here] there is a lot of pretense of tolerance. But their actions show that they're intolerant. And I see intolerance increasing. For everything—intolerance for poor people, intolerance for colored people, intolerance for sick people.

JB: So you think it has gotten worse?

KB: I think so.

JB: And it's more subtle?

KB: Well, it's more subtle than in other nations. In other nations, people, when they're tolerant, they tell you about it, and when they're intolerant, they make it known too. I think in the United States there is some cover-up with politeness.

JB: Yes. That's really interesting because I think a lot of people think that we've made a lot of progress in terms of tolerance and understanding and knowledge over the last ten or twenty years.

KB: Well, we may have made progress in understanding it, but we're not acting with that knowledge.

JB: Right. How do you think that America or your community of professionals is affected by your work?

KB: I don't see myself as having made any, what do you say, impression or impact. I don't see myself as indispensable.

[Interrupted, and discussion of the size of case loads and of how Belani learned to treat children with HIV.]

JB: So Minnesota has very few children with AIDS?

KB: Yes.
JB: How many?

KB: I'd say it's not more than 35.

JB: Okay.

KB: Yes. So what I would do is I would call New Jersey or some friends in Miami. I have friends that I know at the NIH.¹ And I just call and ask them what to do. And then go for meetings, national meetings. That's how I picked it up. And also made contacts at these national meetings.

JB: What do you fear most?

KB: I really do fear that the [numbers of] orphaned children will increase. And that they will suffer. I think it's already happening. They will be stigmatized as being children of parents with AIDS, and I don't know what their next ten, twenty years are going to be like. Perhaps worse than if they did not have HIV.

JB: Right. And what do you hope for?

KB: Prevention of infection and more education. I still feel that we've not even done even twenty-five percent of the education we should be doing. I think that there should be more money for education.

JB: Do you think that needs to take place in schools, or what kind of education?

KB: I think it would be nice to have the media teach us something, instead of sensationalizing. I think TV is one of the best modes of disseminating information, but that doesn't happen in this country. They don't disseminate information, they disseminate sensationalism and misinformation, and sometimes I think if the media was controlled by the doctors [laughter] or health professionals . . . Maybe they should do more through the media--maybe physicians should do more.

JB: Yeah. That's very interesting.

KB: Maybe it is at the high school level. Maybe it's too late at the high school level, but I know elementary school is too early. So middle school.

¹National Institute of Health.
JB: How do you think this time in our history will be remembered?

KB: I think as a time of some sort of failure by the medical profession. I think when we look back we'll say, my god, we were in the twentieth century, we already knew how to conquer so many diseases, and how come we weren't able to prevent further cases of this. I think we have done so much in medicine now since 1950, for forty-five years, and I think it will be seen as a time of failure, and also as a time of learning. There's been a lot of progress in immunology and virology. [There's been] failure on the public health aspect and success on the side of learning, the rapid progress of immunology and virology.

JB: Okay.

KB: Because that's kind of set the whole rapid progress in motion that this epidemic [caused]. We're learning about molecular . . .

JB: You said that there's been a lot of growth in the fields of immunology and virology, even though there has not been found a cure or a vaccine.

KB: Right. I feel that HIV is such a social disease, I don't think we should be--I'm sure that we should be looking at the immunology/virology as it works for each individual, but it's not going to work for a population. I think this is a disease that as a population of humans is preventable, and we have to do prevention in the social realm, in a context [unclear].

JB: Right. Rather than trying to find a medical way to prevent it.

KB: Right, right.

JB: Okay.

KB: That's right, that's the way. Because we are medically sophisticated, but we are unable to do it. Which tells you that it's a lot of human behavior and other things coming into play.

JB: And how would you like to be remembered?

KB: Hmm. I'd like to be remembered that I took care of these children with optimism, and gave them some hope, and treated them like my own kids. I try my very best to make sure these
kids do their normal things, like go to school, do their homework--and [I] try to keep them in a very normal schedule when they are sick. We try to maintain that routine for the kids. That's very, very important. We tell the parents, "We don't want you to disrupt [the] school day for appointments." We'll see them early or at the end of the day. So we try to stress that it's important that they do everything that other kids would be doing. I think that has helped us a lot, that kind of attitude. It gives the child a feeling that everything's okay, if he keeps a routine.

JB: Is there anything else that you'd like to say, would like to comment on?

KB: Ah, it's late in the day. [Laughs]

JB: I think that's all the questions. Thank you very much.

KB: I hope it's useful.

JB: Thanks.