Oral History # 55

An Interview With
Joseph A. Kotarba, Ph.D.

Place of Interview: Woodcreek, TX.
Interviewer: Renee Tappe
Terms of use: OPEN
Approved: JAIK
(Initials)
Date: 5-22-19
AN INTERVIEW WITH DR. JOSEPH A. KOTARBA

RENEE TAPPE: This is Renee Tappe with The oH Project, Oral Histories of HIV/AIDS in Houston, Harris County, and Southeast Texas, meeting with Dr. Joseph A. Kotarba on May 22, 2019, in Woodcreek, Texas. The purpose of this interview is to discuss Dr. Kotarba’s recollection of HIV/AIDS in Houston, Harris County, and the surrounding areas.

Thank you, Dr. Kotarba, for your agreeing to meet with us and for sharing your insights and your research with The oH Project.

JOSEPH KOTARBA: Thank you.

RENEE TAPPE: Let’s start with your general background. Tell me where you were born, a little bit about your family, and your formal education.

JOSEPH KOTARBA: I was born back in 1947 in Chicago and grew up in Chicago all the way through high school until I went away to college. My parents, Walter and Marie, were working-class people. They were second-generation Americans. My grandparents came from Poland. They were the classic story of working hard and being pretty successful.

There were four children in the family: My older brother, Wally, is eight years older than me. He’s retired in Chicago. My sister Mary Ann, who is still teaching. She’s three years older than me. She’s 75, and she’s still sub teaching. She won’t stop. That’s great. She runs the family. And a younger brother, Mike, who’s moved back from China. He’s an engineer, and he’s been working over there, and now he’s back in the States. We get together on occasion, as much as
we can. We go back for family reunions that my sister organizes.

My current family is my wife, Polly. We met in Chicago at a wedding. This was like a working-class Polish scenario. We’ve been married 44 years.

We moved around a lot. We got married, went through graduate school at University of California, San Diego, I’ll get to in a bit. Now we’re here. We’ve got three kids.

Our oldest son is getting married next month in California, vineyards up east of Oakland. Marrying a nice young lady from China.

My daughter just had our second grandchild last week, a little girl.

TAPPE: Congratulations.

KOTARBA: They live in Reston, Virginia, just by D.C. [District of Columbia]. Her husband is an attorney.

Our youngest son lives in Los Angeles, and he’s single, does finance work, and he’s enjoying Los Angeles, which is what I would think single people go there for.

They’re kind of all over. Living here in the middle of Texas puts us in between all of our kids, which is kind of convenient in some ways. We’re all getting together for the wedding, and so that’s going to be a lot of fun.

TAPPE: You said you went to high school in Chicago. Tell me about college.

KOTARBA: I went to De La Salle High School in Chicago, all-boys Catholic high school. That is where I first got interested in sociology, because back in the 1960s, between 1961 and 1965, everything was starting to get very political, very activist-oriented in Chicago. Going to Catholic high school put me in situations of activism. I remember one teacher who was very heavily involved with the
Catholic Workers Union, a heavily, heavily activist group, what today we would call leftist. They were very cool, but through him we got invited to meetings of SDS [Students for a Democratic Society] and Black Panthers. We had all this contact with a lot of activism. At that time, of course, it was very civil rights-oriented. That was quite an experience.

I went from there to get my degree at Illinois State University. I wanted to teach. My interest in sociology started in high school, where we had a course in it. It stayed all the way through. All my majors were sociology. At Illinois State, I graduated in the summer of 1969, and I took a teaching job very quickly to avoid going to Vietnam. My teaching job was in special education, which was a brand new specialty. That was Title I back then, which was totally new in 1969. I did that for a couple of years, and that was kind of fun, but it was hard work teaching mildly-retarded kids.

What happened is that after two years of that, I hurt my back playing basketball with the boys at school. We did a lot of that. Because of that, I had back surgery, and I became ineligible for the draft. That’s how that story adds up.

What do you do when you become ineligible for a draft and you want to get out of Chicago? I said, “I’m going to go back to grad school. I’m going to go to Arizona State and get a master’s degree in sociology.”

That was great. That’s where I met all my mentors who got me directed towards doing ethnography. That was two years, and that’s when my wife, Polly, moved from Chicago to be with me. From there, when I got my master’s degree, I went back to Chicago. I was an assistant principal at a brand new middle school on Lake front, north side of Chicago.
The principal, who was putting together a faculty at the time, called me up and said, “How would you like to come work with me at the new school?”

I had no formal teaching experience. What did I know?

He said, “You’ve got a master’s degree in sociology from Arizona State. You must know something about Indians, right?”

I said, “You mean Native Americans?”

He said, “Yes. We are going to have a whole lot of Native American kids in our school,” because at that time the government was relocating them off the reservations to the big city to urbanize them.

I said, “We’ll give that a shot.” I did that for a year and realized I really didn’t want to do that as a career, which I could have done.

What do we do? Out to California, to San Diego, to get my Ph.D., UC [University of California], San Diego, and three years there.

Then to Houston, that’s where everything started up.

TAPPE: When you moved to Houston, did you start at University of Houston?

KOTARBA: Correct, that was my first University after graduating. I was there for 30 years. Thirty good years, great place to raise a family, good school, growing school. It worked out very well. I was very happy.

TAPPE: You eventually became chair of the sociology department; is that correct?
KOTARBA: I was chair for three years just before I left. I left as chair.

TAPPE: You mentioned ethnography. Explain that to me.

KOTARBA: Ethnography is technically a research method in sociology, but also in anthropology to a large extent. What you do with ethnography is to deal with issues of how people actually live their lives, what they actually do on an everyday-life basis. We don’t collect data like a demographer would, quantitative data. We don’t count anything. We actually study people and ask, “How do you do things?” “Why do you do things in your life?” whatever that might consist of.

What you do is, your data become very conversational, like we’re doing now. It’s very qualitative, which means it’s verbal. What we really try to do is to get people to tell us stories about their lives, their problems, whatever is of interest to us. We analyze those stories in terms of how do people decide on how to respond to problems in their lives or good things in their lives, whatever is happening? We call this interpretive sociology.

Our analysis also consists of stories. That’s getting to be a very, very popular methodology in areas like in medical studies and stuff like that. Instead of just counting things, let’s hear what people’s stories are about their lives. It’s much more meaningful.

TAPPE: In listening to that explanation, it sounds like you’d have much more meaningful, relative information where you can understand the person’s story and what, perhaps, their needs and thoughts are.

KOTARBA: Yes. The other thing we do is that in having conversational interviews with our respondents, you get to hear their wording, their vocabulary, their inconsistencies, and everything else that’s real about the way people lead their
lives, and that becomes valid data for us.

TAPPE: When you were at U of H [University of Houston], you were there during the 1980s?

KOTARBA: I got there in 1979, correct.

TAPPE: Shortly after that, we had the onslaught of HIV/AIDS. I know that a lot of your research that we’ll be talking about today is related to that.

To start down this road, funding was almost nonexistent for anything like that, especially in the early days. How did you manage to get funding for some of your research?

KOTARBA: That’s a good question. Funding was nonexistent because to the people who controlled research funding, AIDS didn’t really exist. It was a gay plague. It was a lot of other things besides an actual disease to be studied systematically.

On the other hand, when you do ethnography, the costs of doing that kind of research are pretty minimal. I don’t need a big staff to analyze and code data. I don’t need a lot of people out there interviewing or doing surveys. It’s very much the kind of research you do yourself with students.

We started this, and you went all the way through with me pretty much being my own researcher as well as research manager, these kinds of things. We basically started to study, the first study we did, out of interest, out of scholarly interest, but also in terms of interest in a group of people who were having all kinds of very strange problems that we didn’t know anything about. As a sociologist, that piqued my interest. My very first study was one, and I think I sent you this, I did with Norris Lang, who was in anthropology at University of Houston. Did you run across him in the article?
TAPPE: I do have the article.

KOTARBA: We were just friends, and we were just kind of talking about things. What was catching my attention as a sociologist were the headline stories about this gay plague going around in 1980, 1981, 1982. In reading the *Time* magazines and *Newsweek* magazines, I’ll never forget seeing the cover stories of this problem. They were having stories after a while that said, “Gay men in San Francisco altering their lifestyles totally in order to fight this unknown gay plague.”

As a sociologist, I was very skeptical at that point because ordinarily people do not behave that way. How do you change your life because of something you really don’t know much about? I said, “Norris, what we’ve got to do because we’re social scientists, let’s look into this.”

He was very well entrenched, if you will, in the gay community in Houston, a brilliant young guy, so he became our contact to the gay community. Back then, that was very important. You just didn’t walk into a gay community, because what is the gay community? He’s a brilliant guy, he’s gay himself, and he had all this great insight into the community that I did not have. Our partnership was great that way. I was learning so much from him about what it was like to be gay: gay lifestyle, gay concerns.

What we did was start a series of interviews with young gay men at risk of HIV. We didn’t deal with patients, per se, because that’s a whole different kind of study.

The men that Norris contacted and we interviewed were very professional, highly educated, very sophisticated young men. We’d go over to their homes or apartments and do these interviews, of course, because how people live is
important to see. Needless to say, the apartments were fabulously beautiful, with
*GQ’s [Gentlemen’s Quarterly]* on the coffee table, all these stereotypical things, if
you will, but they were real.

They were great to hear. It was like these young men were just so
interested in talking about these problems, but they were scared to death. They
were terrified about what was going on, because they didn’t know what was
happening. They thought, “How do you contract this new disease? Is it through
sex? Is it through drugs? Intravenous drugs? Doing poppers at the disco?”
whatever. They didn’t know anything about what was going on except the risk
led to death, and so they were terrified. They were looking to us for answers for
these kinds of things.

Of course, we did not have those kinds of answers. No one did at that
point. They were very interested in finding out more, but we were interested in
talking to them about relationships. We talked a bit about sex. We talked about
drugs a tiny bit. We were just trying to assemble the lifestyle. They were young,
gay men who were like any other young men. They were just trying to put the
self-identity together.

One of the interviews I’ll never forget with one of the younger guys who
was maybe 20, 21, he just moved to Houston from South Carolina, a small town.
He said, “Coming to Houston was like being a kid breaking into a candy store at
night. There was everything to try to experiment with in the Montrose.” It was
clearly, at the time, the core of the culture. He said, “That’s what we do. We try
everything.” The way he put it, “I’m starting from scratch on who I am, and so
it’s not just continuous being a kid. I’ve got to start from the beginning.”
TAPPE: He’s learning.

KOTARBA: He’s learning about the community life, learning about himself, so there’s a lot of experimentation, a lot of activity, a lot of partying, a lot of all those things going on to figure things out. That was kind of like the core of what we were doing. What we were finding out was that young gay men, unlike anybody else, their lives are complex.

When *Time* magazine said all these gay guys in San Francisco were changing their lifestyles, it’s not that simple. That’s where we came up with our typology of why and how young gay men — gay men in general, because we did not just limit ourselves to young guys — how do they change their lifestyles?

What we found are a lot of reasons why a gay man will change a lifestyle, and not just because of fear of this disease. Gay men outgrow a fast-lane lifestyle, if you will. They’re just getting older, like the rest of us do.

TAPPE: Maturity.

KOTARBA: There you go. And fall into relationships. Why do people fall into relationships? Is it just to avoid the risk of disease? No. You want a partner. You want somebody to be with. You’re tired of dating and everything else, like anybody else would do.

Then you have people who would give up the fast-lane lifestyle for other health reasons. It wasn’t the disease, per se. It was kind of like, “Well, I’m having issues with all the other things.” Hepatitis, of course, was kind of an ongoing issue not directly related to AIDS. “These other health issues, I want to take care of myself a little bit better, so I’m going to slow down from doing all that kind of partying kind of thing,” but not AIDS-related directly. It takes very
complex reasoning why people change a lifestyle.

What we were concluding in our work is that we need to integrate factors related to this new disease into programs of part of lifestyle development for gay men, not to simply beat them over the head by saying, “You’ve got to change.” That’s not going to work with anybody. Being a parent, I know that doesn’t work at all. We learned a lot through that. We really, really did. We got that research published.

It kind of led me thinking a whole lot about the folks who were starting to do research then, doing surveys, dropping off surveys in clubs where gay guys would pick them up and fill in the blanks, they were missing a whole lot, doing that kind of research, because they weren’t seeing the complexity of a life where there is a lot of distress going on. It’s not just AIDS that people focus in on. There’s a lot of other things going on in your life.

TAPPE: This is the study where you categorize public life, private life, if there was any switching, such as how they led a private life, and then after HIV came along, they started leading the public fast-lane life. Would you talk about those categories a little bit, please?

KOTARBA: Private life is when you’re not out, essentially. It is a world where you do things on your own. You’re very concerned about who is aware of who you are and what you’re doing. You don’t communicate your life to a whole lot of people, like parents, which has become an issue all the way through all this research. AIDS became something that had a lot of ramifications on the community, obviously.

One of the very important ones we were dealing with all the way through
was the issue of coming out. As you come out, AIDS becomes something which is good for you but also good for the community. There’s a reflexive kind of a movement there. Coming out and getting involved with AIDS publicly meant that you gain access to resources. You can find out who the doctors are working with AIDS patients. We’re going to talk about one in particular in a bit. You also find out what the organizations are who are dealing with all this, and they start springing up all over in places like Houston, especially. Then you find out others like you. You find out other gay men at risk for AIDS or with AIDS in public-health kinds of settings, almost in a way. So you don’t learn about it personally or through discovery or through any type of relationship intrigues. It becomes something that you share with other members of your general community. That’s very positive for the individual when you’re arguing, but it’s also good for the community because that’s how you mobilize politically, if you will, to deal with this kind of problem, because it’s something that’s bigger than you. That’s where I always thought that in Houston, those types of activities were fabulous.

TAPPE: The community took care of itself.

KOTARBA: Very much took care of itself. Nobody else was, except people who take care of others as part of their work: nurses, public health officials to a large degree. City of Houston has very enlightened people in the public health office for the city, very enlightened. For example, they set up one of the very first — it was a desk, I think they refer to it — for transsexuals.

TAPPE: A desk?

KOTARBA: A desk. It wasn’t an office. It wasn’t a big deal. It was a desk, because it included one gentleman, and I can’t remember his name. We would visit with
him, and he was a great contact for things. He was very much into living out the feminine side of him. That was a time when some people did that in a very primitive way. I don’t want to be erroneous in how I say all this. He would wear makeup and dress and have hair like a woman, but he clearly was a just a man, facial hair and everything else, nothing like today. It was okay, because it was simply okay and the city allowed him to have a desk so that he would be able to go out and talk to others, give lectures and speeches and this and that and become a contact with then the very nascent transsexual community in Houston, “community” being “out.” It was just fabulous.

One of my personal experiences with that was the first time I met him — some nurse friends of mine brought me over to meet him — they all gave him a hug when they met him, or her. I didn’t know what to do. I said, “This guy is clearly still a man, and you men don’t hug men.” This is going back, now. So I extended my hand to shake his hand, and he gave me a big, warm hug, so that ended that problem.

TAPPE: She worked with the city — am I correct? — in terms of outreach or education?
KOTARBA: Yes. It was an effort to reach that part of the Montrose community, which of course then was everybody’s perception of where these folks are.

TAPPE: To touch one more time on this particular research that you did in terms of the changing of the lifestyles, the public versus private, the impact that HIV/AIDS had on their lifestyle, did you see those changes that they were reporting in San Francisco and New York in Houston; that there were any major changes in terms of how men lived their lives?

KOTARBA: Oh, yes, very much so. It was a matter of awareness primarily, I would
think. You hear about these things that you’re at risk for. To do that by yourself is terrifying, but to know that there are others at the same risk like you, that sharing is so important because that allows you to then move along and learn more. That's how you learn more, from others, not from your own experience. The changes were happening all over the place.

Example, one of my immediately following activities in terms of HIV/AIDS was working with the first NADR [National AIDS Demonstration Research] Project in Houston, and you gain a bit of a reputation for doing this kind of research, and I was an oddity. Nobody was doing this stuff, in sociology, at least. The NADR Project was an interesting experience. I did work with them for a couple of years. It was the first federal grant to do ethnography with people at risk of AIDS. It was already expanding in terms of the scope of who we were talking with. The grant came to a private organization, a for-profit organization, which was very unusual. Usually these things go to universities, these types of grants, public health departments especially, but Affiliated Systems was the company who got this. Isaac Montoya was the president of Affiliated Systems. He contacted me and said, “I’ve got this grant.” He got a huge grant. “I need people to do some ethnography, and how would you like to come work with me and set up the ethnography portion of the project?”

I said, “Sounds good,” because here’s a guy with money. What that means, I can hire students to work with me, and I get all those good things because of those kinds of resources you don’t do when you’re a lone ranger like I was with Norris. It was a very corporate kind of setting. It was extremely sophisticated. We’d have regular meetings like they do in companies and things.
What the NADR Project did — and they ended up with 60 or so of these projects around the country — the federal government gave these grants to entities like Affiliated to do two things, one of which was to conduct research on people at risk of AIDS. This was in 1981, 1982, maybe up to 1983, so it was “AIDS” already. To do the research would be to find out what the at-risk behaviors are. Drugs, sex, rock and roll to some degree even, I looked into. We weren’t focusing just on gay men. We were focusing on the behaviors, which was very enlightened. So it was people who use intravenous drugs and probably share. People who do other types of drugs that lead them in that direction, the poppers and speed, things like that.

[END OF AUDIO PART 1]

TAPPE: You mean that would lead to the IV [intravenous] drugs?

KOTARBA: Correct. People who are engaged in having sex with men, or partners of men who have sex with men, as we started seeing the links, the networking of these risks. That was very interesting. That brought us into the arena of male prostitution, especially young kids involved in this in the Montrose at the curve by McDonald’s.

TAPPE: Over in the Covenant House area?

KOTARBA: Right across from the Covenant House, right where they would go for resources, then get back out to the streets.

It was a very widespread project. We were finding out a whole lot of data, a lot of things about these people, these men, older men, younger men. The other side of this was intervention. We were to develop ways of intervening to help minimize risk among the people that we’re studying. We would set up these
centers. We had several in the Montrose, we had one up in The Heights, we had one down in the Third Ward, which was really pretty good coverage.

What we would do is, we would bring at-risk people into the center for the interview, formal interview, while we’re also delivering public health information and materials to them. For example, condoms all over the place. I even had a bowl of condoms in my office at school, and no one made anything of it. The people would say, “What’s that, Joe?” That’s what we did. You’d just have them around, pass them out like candy. Explanations how to use them, and so some of that primitive instruction involved the banana. But all the banana did was bust a hole in it.

Then it got more sophisticated with audiovisual kinds of materials and outreach to the community, other churches and groups to present these kinds of instructional activities.

In talking about what “at risk” means, we got involved in issues of why you don’t share, how to clean needles, which at the time was not officially approved. We did not provide needles. There was no exchange or anything back then, because that was illegal. We’d teach people how to protect themselves. If you have a partner you’re sharing a needle with, you’ve got to make sure that only you and he or she share that needle and why that’s important.

How do you clean it? So we’d also give bleach out to people, little bottles of bleach and teach them how to do it. That was really pretty cool that we did all this. I had several of my students do that type of outreach. “Outreach workers” was the technical term for this. It worked out really well.

One of the drivers at National Institute on Drug Abuse, the federal agency
running NADR, was to involve people who were actual at-risk people as part of your team. Very insightful at first, because they know the streets. They know what’s going on. They know the individuals and the risks. But they’re also former users. Hopefully, former users. We always had that issue of, what’s it like to work with staff that themselves are at risk of what we’re talking about? You may not tell us that you’re still using. That got kind of touchy, and so we were very careful putting our staff together and very careful monitoring them, not only to supervise them, but also to be there if they’re at risk.

TAPPE: To keep an eye on them.

KOTARBA: For their own good. A little bit of paternalism built in, but that was how that was going back then.

I worked with Affiliated Systems for about two years. We published a number of things on the very formal way of engaging individuals for AIDS work like this. We did not work with any of the hospitals or clinics or things like that. This was very much out in the streets, and we had money, so we would pay a guy $25 to come for an interview. $25 was a lot of money if you’re a user. If you were a kid, that’s a half a day out on the curb. We knew how many of our respondents were going to take that $25 and go buy.

We talked a lot about that. What does that mean? Are we enabling anything?

TAPPE: The ethical part.

KOTARBA: We came to a very good conclusion — at least I did — and said, “What we don’t know, if I were to come in for an interview, middle-class Joe Kotarba, we don’t know what I’m going to do with my $25. Let’s not worry about what
anybody does with it. That’s their business at that point.”

TAPPE: Your goal was to gather information and to help educate these young people.

KOTARBA: To maintain the contact — you’re exactly right — is worth the risk of anything happening like that. Let’s face it. If a user is going to use, he’s going to get his drugs any other way anyhow.

There were a couple of occasions, if I may. A young guy at the end of the day, at 5:00 o’clock. I did an interview with him and everything. He said, “Can you give me a ride?”

I said, “Sure. Where are you going?”

“Well, I’m not sure.”

“I’ll give you a ride.” We do this all the time. “What are you looking for?”

This was up in Fifth Ward. It was a scary place. Different back then, and he’s a white kid.

He said, “Just drive down the street,” and he’s looking around. You know he’s looking around for a seller, I quickly figured it out.

He’s looking around, and he said, “Stop. Here it is. Could you wait for me? I’ll be right out.”

That sort of gets a little touchy, now. I said, “I’ll wait for you.”

He went in, in and out. He got out in about two minutes, and he kind of rushes out pretty quick, jumps in the car.” He said, “Now you can take me back.”

I facilitated him doing a buy. What did that mean in terms of ethics or safety or anything else? That’s one of those things you’ve got to learn to live with if you’re an ethnographer and you want to study things that are difficult. What
did I do? I helped this kid make his contact. I also got him out of there, which is always good, because you don’t want to hang around at a sales location. That was okay. He wouldn't tell me the whole thing.

I didn’t talk a lot about these activities at home, as you might guess. It was okay. I wasn’t taking the exceptional risk.

On occasion we would go to where guys were shooting up and hang out there and learn what it’s really like to shoot up, but you have to go see to know.

Do you want me to tell you a little bit about that?

TAPPE: Yes.

KOTARBA: I’ll never forget when my No. 1 assistant through this time — his name was Jay Johnson. He’s working with the School of Public Health at UT [University of Texas] Medical in Houston. Jay Johnson, just a tremendous guy to work with. Published a lot. I’m godfather for his kid. He took me to a dusty old place in Fourth Ward. There’s some old black guys sitting there, old heroin users. They’re sitting there, and they’re shooting up. Jay had great trust with these guys. We were not very intrusive into the setting. So we came in, hanging out, talking to these guys. The guys are shooting up. Before they were shooting up, you can tell that they’re heroin users, kind of mumbling and incoherent and always kind of looking out for what’s happening. Once they shot up, they became among the most articulate people I’ve ever communicated with.

TAPPE: Is that right?

KOTARBA: Yes. They were different people. They were making great sense, would be able to tell good stories. It was kind of like they were really up on it before they took the nod. I’m saying, “This is why they do it. They become exceptional
people when they’re high.” They don’t become high only. They become something different, and they’re able to talk and create conversations and answer questions, which I would have never expected.

TAPPE: That’s interesting. I would think it might be the opposite way.

KOTARBA: Of course, that didn’t last long. Then they began to nod and lose that high pretty quick. Still, it was kind of like that’s the power of a drug like heroin. You become something different. It’s not only the actual drug effect.

Outreach workers went into the streets. This is, again, with the Affiliated project. They were good grad students, and they knew where to find people, for one. For two, we had contacts that we would trace. It wasn’t all that difficult locating folks. Sometimes we would find them in waiting areas like people over at — who were not minors. There weren’t too many people at Covenant House who were not minors. So what we did was, they just kind of went out into the community and hang out in clubs and just everything else, ask bartenders, and just general kinds of outreach.

TAPPE: They might point you in certain directions or tell you to go talk to this person or that person.

KOTARBA: Certain direction. Some of them were in less formal groups. A lot of us would do things like locate women who were users and also prostitutes, one and the same. It was just general outreach and being courageous and getting out, but what attracted them, of course, was $25. You pay them, they’ll come.

TAPPE: And there was a word on the street, they’re looking for you at some point.

KOTARBA: You’re very correct.

TAPPE: You’ve written and/or presented a number of papers related to the care of HIV
patients. Could you walk me through the concerns that some of the healthcare workers had during the early days of the crisis, that they had for themselves as well as for their clients, and how maybe it has evolved through the years?

KOTARBA: Great question. Let me preface my answer by saying how I got involved with that. After working with the NADR project for two plus years, I was contacted by nurse researchers at two schools: Texas Women’s University, and that person was Diane Ragsdale. I also worked with nurses at UT School of Nursing, and Brenda Hale was the key person there.

TAPPE: I was going to ask you if they worked together with you. But no, separate research projects?

KOTARBA: Separate research projects. I don’t remember the time order. What they were getting involved in was, of course, AIDS research, but being good nurses, they wanted to do it right, and nurses have turned out to be the very best colleagues I’ve ever had in research. They’re careful, conscientious, committed. To teach them ethnography and how to manage ethnographic teams, they know how to deal with directives, and they were just so fabulous to work with.

What we did was, in terms of Diane Ragsdale and TWU [Texas Woman’s University], they receive small grants from the university to do research. They basically had their own graduate students to help out. They needed me as a consultant kind of person to work with them on how to do this kind of research. What was nice about both groups is that they had access to clinical settings. It was Diane Ragsdale who introduced me to Park Plaza. It became a very central location to study issues of caregiving to PWA’s [person with AIDS].

TAPPE: Tell us about Park Plaza.
KOTARBA: At one point, if I remember correctly, it was pretty much the second largest private AIDS unit in the country, because everything else, of course, took place in public hospitals. The No. 1 private one was some place in San Francisco. It was very interesting that Park Plaza set this up, and they had a number of physicians involved with setting all this up and not only delivering care, but trying to figure out what kind of care to deliver. We would hang out there. We had access to a clinical setting, which is tremendous if you’re doing medical sociology. They welcomed us in.

What we found was, in giving care, the nurses, of course, did most of the hands-on kind of care. Those were the days when some nurses were very leery of working with PWA’s. I’d actually see them do things like put on double pairs of gloves in case one broke.

Being an ethnographer, my concern was not them or why they did it, but what was the reaction of the patient to seeing that being done? The reactions were tough to hear. It was like when the nurses would do that, the general response from the patients, young men, was to feel that much more isolated because “These people are distancing themselves from me regardless of actual risk” kind of a thing.

We got involved. Again, I passed that along to the nurses who really take advantage of these kinds of insights clinically. They passed the word down, “Whatever you do, don’t be sitting there playing with your gloves in front of a patient. Everybody knows you need to wear gloves, dealing with a contagious issue, but do it on your own. Show the respect for them that you’re not holding anything against them. It’s their disease that you’re dealing with.”
The nurses, best people on earth, admitted they never thought about that.

That was one of our main clinical activities, was to just talk to the nurses and the staff, other staff people, about how their patients are seeing what’s going on and what’s going on in their heads and their lives. Medical people don’t always talk with their patients that much, even social workers to some degree. We got a lot of insight into that, and that’s where we published a couple of papers about quality of life. That was the big thing we studied at Park Plaza. We witnessed different styles of coping.

TAPPE: I’m glad you brought that up, because I wanted to ask you about that. You had the activist, the timekeeper. If I understand your paper correctly, this is how some of the clients would manage themselves.

KOTARBA: Management styles. This is the way we do research and especially analysis in ethnography. We develop these typologies of different kinds of people, different kinds of responses, different styles of response.

The management styles include the loner. The loner is a patient who rejects and avoids social interaction. “Leave me alone. I’m just going to die. I don’t want anybody around me.”

Then the activist, somebody who is running three different social or activist programs from his bed at Park Plaza Hospital, on the phone all day long.

The victim. The victim manages survival through a posture of dependence. Very childlike responses, and sometimes they drive nurses and other staff people crazy because they’re somewhat tough to deal with if they’re constantly hitting the button for things.

The mystic manages life by defining an otherwise unfortunate situation
spiritually rather than medically. A whole lot of guys like that in terms of, “This is my life. This is my lifestyle. I can be a better person if I deal with this properly.”

TAPPE: When you say “spiritually,” you’re not talking about religion? You’re talking about spirituality?

KOTARBA: Spiritual ideas sometimes acted upon through religion.

The timekeeper, just waiting to see what’s happening and just biding his time, knowing that things are not going to get better.

Of course, the medic is a person who just reads all day long and is on the telephone asking questions and knows more about AIDS than most of the healthcare workers did at that point.

TAPPE: Were the nurses able to adjust to each of these types of personalities?

KOTARBA: They adjusted better when we would take these findings and talk to the nurses about that. Here’s a way of seeing them in terms of their differences as selves and as personalities in dealing with AIDS as opposed to the obvious fact they share the same disease. Well, just because they all got the disease doesn’t make them the same, as people. They knew that, but we kind of helped them refine their understanding of why these guys behaved differently in terms of the responses to AIDS. That was really kind of neat that we were able to do that and I was able to contribute as a sociologist, not as a healthcare worker.

TAPPE: I’m sure that helped the healthcare workers as well as the patients, the clients, to fit together a little better. No judgment on how you’re dealing with it, whether you are always on the phone, or knowing more than somebody else, or whatever the case may be.
KOTARBA: Exactly. One of the messages that we were trying to pass along was, you’ve got some very sophisticated patients here, and they’re highly educated, and they’ve got a problem, and they’re going to deal with it like sophisticated people do, as frustrating as it is.

TAPPE: When you were dealing with the nurses and doing your research, did you hear much from the nurses about the concerns that they had for themselves, especially early on in the disease, for their own well-being?

KOTARBA: Especially early on.

TAPPE: Medically and emotionally?

KOTARBA: Of course, the double gloves, the original intent in that was to help prevent needle sticks, which is not a good way to prevent needle sticks. Latex is pretty porous.

Yes, those are the kinds of concerns they had: the needle sticks; getting too close and sharing too close a space, you never know when there’s going to be spit or vomit involved. Those kind of very general things at first. After a while, nurses — you know, they know how to figure these things out. With our help, as limited as it was to them, we told them the kinds of things that would help them not only protect themselves, but protect the relationships with their clients, or patients.

After a while, nurses would be better about these kinds of things. Maybe most importantly, nurses were becoming more comfortable talking about these things with the patients. “I’ve got to be really careful giving you the shot. Now, don’t move, because I don’t want to poke myself either.”

TAPPE: Sure, and they actually understood that, the clients did.
KOTARBA: They understood that.

TAPPE: Did you observe or investigate or talk about the emotional impact or psychological impact on the healthcare workers of taking care of people that at that time were going to die, and so they probably lost a lot?

KOTARBA: They lost them all.

TAPPE: Do you remember talking about that or addressing that with these folks?

KOTARBA: Yes and no. In conversation, yes, these kinds of issues would come up. “What’s tough about the job?”

Doing the job itself, nurses don’t show that kind of thing. They can’t show that weakness, if you will, to the patient, because the patients are pretty vulnerable. Nurses are pretty smart about this kind of thing. They kind of hold off on these things, and the doctors had the same experience. There’s a buildup of the stress of dealing with young people dying and you can’t do anything for them. It took a certain kind of nurse to stay with that. There was a lot of turnover at first in places like Park Plaza. After a while, the nurses said, “This is my mission. This is what I do, and I’m going to do the best I can and take care of myself the best ways I can.” They could handle this. They have their own sources of comfort, and nurses are good at that among themselves, so that perspective helped a lot of them cope.

TAPPE: Of course, going into nursing, these folks know that they’re going to lose people along the way. I know that with some of the care teams that were set up either through churches or community organizations, they had to deal with the same thing. They’d go in and take care of two or three different people, and inevitably they would lose them, and the numbers just continued to pile up for
KOTARBA: One of the most difficult examples of just what you’re saying now is a gentleman — I’d met him once. He was a dentist who was providing dental services to PWA’s. I think it was the Methodist church in Montrose.

TAPPE: It was with Bering. Bering Dental Center, Bruce Smith.

KOTARBA: Yes, I remember talking to him. I said, “How do you pull this off, because you’re right there in somebody’s face?”

I remember one thing he did say was, “You don’t know what any patient is carrying when they come into your office for dental care, so you’ve got to be careful in general.”

That self-care took place at the same time dentists in general were starting to wear masks. It became a big deal. And glasses, especially to keep things from the eye.

It was his mission to do that. I don’t remember his exact wording, but he made it real clear that somebody’s got to do this.

TAPPE: He and a group started that dental clinic, and then Bering started a day care center so the client could stay there for the day while their partner went to work, because they had nowhere to put them and they needed some supervision, many of them did. His name is Bruce Smith. He did a great job with that.

KOTARBA: Is he still working?

TAPPE: He’s still working. He still has a private practice.

KOTARBA: It was just a remarkable practice when they did that, because most dentists then did not take the risk.

TAPPE: Nobody wanted to do it, but he was one of the first, and he, I believe, helped
develop some of the safety procedures.

You’ve talked about this in a roundabout way, but I wonder if you could elaborate. Through all the research that you’ve done, you’ve had contact with a number of people with HIV/AIDS. In the different ways that you’ve looked at them, how would you describe life through their eyes? Is that something that you could address?

KOTARBA: The best access I got to what you’re talking about came in our study of the hospice called McAdory House. It was very small. They only had two beds, I believe, at that time. They were just expanding to four, a tiny little building. Through that type of a very intimate setting, we were able to hear a lot about these feelings and perceptions of both the patients and the care deliverers. For the patients, I hate to say everything is amazing, but everything was amazing. For the patients, it was a complex kind of experience to be at McAdory House. The dying patient was not just lying there doing nothing. It was very difficult for them because they had to figure out how to relate to the volunteers, especially, working over there.

There were issues for some of the patients in terms of relating to the volunteers, which I did not originally expect. Many patients objected to those volunteers who really wanted to get a close relationship going with the patient. Patients would say directly, “They’re making out really well. They’re feeling real good about themselves. Do-gooders.” We’ve heard that term used a little bit. “But there’s nothing in it for me, because when I go, I go. I’m the guy who’s going to die out. What’s in it for me to expose my sense of self to a volunteer who wants to get intimate with me?”
I mean, to hear this kind of talk was like that’s reality. That’s what ethnography is really looking for, that level of reality. So you’d have problems working with volunteers. Of course, you had volunteers who’d come in with their religious kinds of baggage. The person dying with AIDS not only has to deal with AIDS. You’ve got all these people around trying to define reality for the patients.

[END OF AUDIO PART 2]

TAPPE: For them.

KOTARBA: That’s why they’re volunteering. That stuff comes at somewhat a high price tag for the PWA’s. The staff were great over at McAdory House. There wasn’t a lot of staff, but they did their job. They were great. The volunteers were something else. That’s why I wrote the article about some of the great paradoxes and ironies in a place like McAdory House, which was revolutionary in terms of healthcare delivery. Old straight guys taking care of young gay guys who were dying, it’s not supposed to be like that. Traditionally, it’s the other way around.

McAdory House, at least at that time, was affiliated with a Lutheran church, not in any heavy-duty way, but affiliated. And you can say it’s a Christian kind of a setting. You have chaplains walking around.

Well, they had all kinds of religion and spirituality going on over there. Buddhist guys coming in and meditating, Catholic, Protestant, and Jews praying, all kinds of different spiritual people visiting, and it was okay.

See, all these things I’m talking about were okay in that setting, and you have patients who were wanting to try nonmedical potential cures or treatments. In a hospital, it would not be allowed. At McAdory House, it’s okay. All those
kinds of things that would be unexpected in other kinds of healthcare settings were okay at McAdory House because there were no rules. There were no barriers to experimenting over there, because these guys were dying.

You’ve got these middle-aged and older, white guys, straight guys, sitting there talking to a gay guy for the first time in their lives, which I found remarkable, except not remarkable, because I’m sure they talked to gay guys before, but not openly. You’d see them talking and asking questions like, “What’s it like to have a boyfriend?” type of thing. They all grew because of this open conversation. That was the real miracle of McAdory House. They all grew.

We got that study. The study was just fabulous. Because of AIDS, people were growing, on all sides, and that was good.

TAPPE: It took a while. I remember, when it all was first coming about, so many comments about, “This is God’s wrath,” “Because of your behavior, He wants you to die.” I agree with you. It opened up lots of communication and helped people see each other in a different way.

KOTARBA: Because they were able to talk, and you knew why you were there and why he was there, so motive was not an issue of any kind, not a big issue.

The related issue to this was family. Very tricky for the Park Plaza staff, but also for McAdory House staff, I remember. It was like how do you tell your parents you’ve got AIDS without telling them you’re gay? Tough to do. The weirdest things we witnessed were a number of cases, of course, where a young man would disclose being gay to his parents because of AIDS, both bullets at the same time. To hear stories about how parents say, “I never want to see you again. Get out of my house,” to your kid who’s dying, that was tough to take.
TAPPE: But it happened.

KOTARBA: That was really tough to take for me. It’s kind of hard to really see. I can’t imagine ever doing anything, but parents disowning their kids within those circumstances just was kind of like, “Your kid is dying. Give him a break,” but parents would kick them out. Then you’ve got situations where parents would come back to McAdory House to visit, but that was rare.

I was not at McAdory House long enough to see a lot of these kinds of things, but on a couple of occasions you’d have staff who was very influential in making contact with the parents and saying, “We’d really like to have you come and spend some time with Bobby. He’s not feeling good now, and he really would love to talk to his parents.”

Well, you’d have some parents you dealt with who were trying to mend things with their son. Not a lot but to see a couple of those cases happen, that was wonderful. Parents were able to visit their kid not as a gay person hanging out in clubs or being bad, but by seeing their kid in a bed sick. I think that enabled parents to talk to their child.

TAPPE: Now you’re dealing with life and death.

KOTARBA: Exactly, and it’s your kid now. It’s not a gay kid; it’s your kid.

TAPPE: I know that some of the other people that I’ve spoken with have talked about that being particularly difficult, where the parents had to find out that they were gay and that they had AIDS both at the same time. The shame that was involved.

KOTARBA: Where do you start?

TAPPE: I think this goes to the impact of being gay, at least in the past. “I’d rather tell my parents I have AIDS than that I’m gay.” That’s a tough one. That’s the
KOTARBA: Instead of coming down as a fancy professor and being judgmental on those parents for being close-minded, in seeing the parents and talking to them a little bit about this, you get to understand this was a big shock. I never really got a sense that the parents didn’t know some of this already. The kid takes off, goes to the big city, doesn’t come around, never brings a girlfriend home. Parents are not dumb. But to have to actually face that is a really difficult thing because those parents are real people.

TAPPE: Dr. Kotarba, while you were doing your research, did you find any significant difference in how men with HIV dealt with illness versus the women? How were they treated by the healthcare workers and by society? What differences did you see between the two genders?

KOTARBA: There were some significant differences just by gender, but also in terms of race. We spent most of our time interacting with women at risk of AIDS with African-American women, not that there weren’t Anglo women who were engaging in the same behaviors, but we just had more accessibility with the African-American women. The nurses were very good with this issue because they were able to locate the places where we could locate women who were basically in the streets doing drugs and other things.

The women were different in some ways. Overall, they are much more vulnerable, much lower class, if you will let me use that expression, than the men were, overall. The women were involved in all kinds of illegal behavior that was very risky for them. They seemed to spend a whole lot more time in jail than the men did. They were in jail for a lot of reasons. If they had a heavy drug
dependency — again, heroin was a big one back then — they would engage in a lot of boosting, which is going into stores, shoplifting, stuffing things into your coat, you walk out. They would be involved in all kinds of prostitution whenever available, which was tough for them because quickly over time a woman who is living that kind of lifestyle is not very marketable as a prostitute, if you will.

What they would do, if you’re leading that type of difficult lifestyle — I could say the same thing for the men — you organize your everyday life very specifically. A typical every day for a woman who is doing heroin and everything else is getting up in the morning. The first thing you do is try to use whatever you have left of yesterday’s hit of heroin. Then you go right to the stores when they open up, and you want to boost early in the day because that’s when not a lot of people are shopping at that time, and so no one is thinking anything is wrong. They’re busy setting up displays and this and that, so you can boost in the morning.

Get done with your boosting, get out of there, go fence your materials, sell them when you can or trade them, whatever the market will let you do, and then you shoot up right after noon, and that might be the rest of your day.

If you shoot up, you can always have an evening activity, which includes maybe more prostitution, more stealing of different kinds, sometimes selling. Women, the ones we dealt with, were heavily involved in distribution of drugs during the day and would be able to get some amount for themselves getting out there, which is high-risk. They would do a whole lot of high-risk stuff.

Some of the women had children. The difficulty there is that it seemed in general that the women did not have their children with them. They would lose
them to the state through the government. They’d have their parents, their
grandmothers, taking care of the kids. They were in general in no position to take
care of kids. That was just a tremendous distress for them to not have their kids
with them, and that was tough to deal with that. They rarely got into a situation
where they can generate any income that they could send for their kids.

TAPPE: Because they were just continuing the same cycle?

KOTARBA: That’s it. The absence of kids was a real distressor for them.

TAPPE: The ones that were HIV positive, how did they deal with their illness versus the
men? Now, as you said earlier, some of the men that you dealt with were well-
educated, had more money, perhaps had more support from friends and family
and community. Here you’re dealing with a different demographic completely.

KOTARBA: It was the drug use that would kind of answer that question so that the men
who were shooting up heroin and the women shooting up pretty much lived the
same level of lifestyle so that risk of AIDS was not a priority. Getting a hit was
the priority. They’re addicts.

That happened for men too. If they were of a higher social class, that’s
like the gay men, then they can deal more forcefully with the issue of HIV/AIDS,
but if you have lower class people we’re talking about in terms of the women and
the men who are shooting up — they’re not going to organize. There’s no
community. There are individual relationships with other people in their world,
very few of whom are healthy, and so the men and women who shoot up would
share that. It’s that addiction that put them in a position of not dealing with their
HIV, and the men and women, for example, would readily say that, “I won’t use a
condom if a guy pays me another 5 bucks,” putting two people at risk, but that’s 5
bucks. That’s a hit.

TAPPE: Did you see some of these people end up hospitalized strictly because of HIV? Now, they probably weren’t at the private hospitals, but at Ben Taub?

KOTARBA: But at Ben Taub, yes. Towards the end of all this line of research, we started seeing some women at Park Plaza. Not many. A few, mostly women of color. I don’t want to overgeneralize on limited experience, but you see occasionally an Anglo woman who would be a speed freak and be very skinny, and she’d be at Park Plaza, and they were very difficult patients for the nurses to deal with. It’s at that point that our research, for a number of reasons, pretty much ended.

TAPPE: Your research at that point on this topic?

KOTARBA: It moved into different directions. I did one project with AIDS Foundation Houston. I had a class of students, and we did an evaluation of their intake process when people would go there. They were always packed with people, and over time, you see a variety of people at AIDS Foundation Houston. We did an evaluation of how well that works in a very technical, organizational sense. That was really a good thing to do, so I taught the kids some good sociology, but also we learned that’s where the whole AIDS thing was changing. It was becoming more formalized, and for good reasons. It was no longer a missionary effort, less so a missionary effort to deal with people living with AIDS. It no longer had to be that way.

TAPPE: Finally some money was coming in. Federal money was coming in. Formal programs were being established. Healthcare got better. Yes, it has shifted quite a bit.
KOTARBA: And the people, especially the women who were coming into AIDS Foundation Houston at that time — and we’re talking late 1980s now — felt very comfortable going to AIDS Foundation Houston as opposed to a city clinic of some kind because everybody was cool about things at AFH.

TAPPE: In your AIDS-related research, you openly addressed the crisis because this was a part of your job at the University of Houston. How did the administration there and your colleagues deal with you dealing with AIDS? You were probably the lone wolf out there at that time.

KOTARBA: Kind of, Norris and I.

TAPPE: Tell me about that whole situation at U of H with your students as well as your colleagues.

KOTARBA: I can say very clearly and directly that I can’t recall any problem I had with my colleagues in my department or the administration over dealing with this AIDS issue at all. Kind of remarkable, thinking back on all of that. I can’t recall anybody even sniffing at me or saying something like, “Whew, what have you got going down there, Joe?” kind of thing.

It was absolutely nothing like that for a lot of reasons. One, sociologists, that’s what we study: issues that can be seen as distasteful or weird by other people.

On the other hand, the administration at U of H was wise enough — I’m generalizing a bit — but they’re wise enough to realize, “Hey, this AIDS is getting to be a big thing. We’ve got a couple of guys getting involved with it, doing some research on it.”

Then over time, of course, as I started generating resources and I got my
own grants from NIDA [National Institute on Drug Abuse] to do this kind of research, “Hey, this guy is bringing in money to pay for grad student support while doing something that’s great visibility for the university that we’re involved in this. We’re out there in the community.” So they had no problem with this at all.

Students had no problem for the most part. I guess I was kind of a mentor or a faculty rep for a group that didn’t last all that long. That was a group that Laura Hulin was in the middle of helping set up. She and her friend Darlene Hurt, she’s a very close friend. We worked together on this. They set up this group, and I didn’t have that much to do with the group except to be their faculty sponsor.

What happened was that I put together my course, and that became my main activity at the university, this big class. It was packed with kids the first time I taught it, 125 kids in there, Sociology of AIDS. I brought in a different speaker every class. Brenda Hale came in. Her husband, Miguel De Kuña, came in from the medical center. They talked about the biology of AIDS as much as we knew.

God bless, I’ve got all this stuff on tape. I taped all these lectures and saved them. Talk about an archive.

So I had these experts come in. This was great PR [public relations] for the university. I got a teaching award for innovative teaching and put together a curriculum. I taught the course several times.

I’ll never forget the first time I taught the course, some conflict erupted in class, and that was between the men and the women in class. It kind of surfaced
after a while that it was going to be the gay men in class and the lesbian women in class started going after each other a little bit. So I put together a panel. I said, “We’ve got to bring this out. We can’t let this simmer.”

I put a panel up there, boys against girls type of thing. The issues started coming out. The political issues that were involved started to come out about AIDS. The men said, "I’m sorry, this is a gay men kind of thing at this point. This is relevant to us. We want to have a say-so on what happens and how this stuff is handled.”

The women were saying, “No, you guys are getting all the attention over this whole thing. The whole thing about alternative lifestyles and gayness and lesbianism, hey, we’ve got a dog in this fight too,” as we would say down here. “You guys are getting all the attention on this. We’ve got issues too, and we’re extremely helpful to you guys,” and they were. They were right in the middle of fighting AIDS support. “We want a piece of the action,” so to speak. They said it in much clearer terms.

So they had a little bit of that political thing going on back then. We talked about that in class and how of course you have to understand who your enemies are. You’ve got enough enemies out there without making new ones. That kind of resonated very quickly.

TAPPE: Especially in your own community.

KOTARBA: What happened is that — again, this is kind of what AIDS fomented organizationally — that’s where the men started organizing themselves into a group, student group, interest group, and the women did too, which was great, because they were able to deal with their own concerns organizationally, and the
university was pretty cool sponsoring those kinds of groups at that time, perhaps not totally in favor.

TAPPE: But they didn’t shut it down.

KOTARBA: Yes. Anytime students want to get together and do good things — and they had to, of course, show that there was public service involved in this — the university was pretty okay with that. That’s where all these other student groups started springing up, I think, at U of H. Less need for our original AIDS group and less need for a sponsor like me, old straight white guy. “We don’t need you anymore,” which was great that they didn’t need me anymore. They were taking on the responsibility for their organization.

TAPPE: Were the men and/or the women out to educate students on campus?

KOTARBA: Yes.

TAPPE: To deal with teaching safer sex? Condoms? What were they doing during that particular time? Do you recall?

KOTARBA: Not a whole lot at that point except kind of like instructional discussions among themselves, the gay men among other men. There wasn’t a whole lot of big outreach at the university at that point. This is blurry in terms of my memory of this. Eventually these groups would be working with the student health center in developing programs for the student population in general at the university, but that was an eventual kind of a thing. In terms of a lot of outreach to the university in general, I don’t think at first. I think it was kind of they were trying to get themselves organized first.

TAPPE: I see, and then went from there.

KOTARBA: Yes, and that seemed to work pretty well. It took off, which is great. How
much of this was AIDS-instigated? It was at first, but the other issues started coming up again in terms of discrimination, in terms of “Could we have more classes and things related to this or that?” but that was between them and the university pretty directly.

TAPPE: Not AIDS-related, but more of the community?

KOTARBA: Not totally. It was community-oriented. That seemed to be the pattern, and that seems to be clearly the case right now. Nowadays, of course, I tell my kids, “Will you stop adding letters onto LBG [lesbian, bisexual, gay] plus, plus, plus? I can’t keep up. I don’t know who all those people are.”

They say, “Well, you’ve got to get with it, Dr. K.”

“Well, I’m too old.”

So that’s where all that’s at now, which is really, really good.

TAPPE: It’s all another world.

KOTARBA: It is. I just think back, as we’re talking, to how primitive all this was 30 years ago, where they’re looking to me to explain things that I knew very little about, myself. If somebody gave them attention and cared a little bit, that was the real important thing for them back in the 1980s, early 1990s.

TAPPE: For you, what pulled you into the gay community was the issue of AIDS.

That’s when you and your colleague went, “Why don’t we look at this?” and just one thing led to another. You learned a lot.

KOTARBA: You’re exactly right. I credit a lot of my colleagues in other cities with doing the same kinds of NIDA-funded research. We really created literature on this is what the gay community is all about.

Before that, there was one book, *Tearoom Trade*. It was almost a dirty
book, the way people in sociology were treating it. Laud Humphreys was the
author’s name. The guy did this study of men who would at lunchtime leave the
offices downtown, go to the park, go to the men’s room in the park, go and have
sex with another man, come back, put the ties back on, go back to work.

What Laud did, and it became a big ethical issue, and that’s why I’m
raising this point. What he did was that he took down the license plate numbers
and traced some of these guys down and went to their houses to see where they
lived, who was going to answer the door.

Today you won’t even go to jail for that. You’d get stoned. You just
don’t do that kind of covert research anymore.

Laud Humphreys did that because he just wanted to find out. His
intentions were good. It was how do we explore this otherwise completely hidden
community behavior? It was in the community, the behavior. He did this, but
Laud Humphreys’ book became the bible on how to discuss ethics in social
research. Interestingly, “This is how you don’t do it” became the message, and
unfortunately it was a gay guy doing gay research. That became the model of bad
ethical research.

TAPPE: He was a gay man doing that?

KOTARBA: Laud was gay. What straight guy back in the 1970s, middle 1970s, would
conduct a study like that? It wouldn’t have happened.

TAPPE: That is, as you know, such a stereotypical idea of what gay life is like. Did it
exist? Yes. But the community is so much more than that.

KOTARBA: Tons more. There was a community back then. It just was all the secretive
behavior of men. Nobody was out. Again, it became seen as dirty research about
a dirty community. That’s pretty much been shelved after all these years as just
an exception to the rule. You just wouldn’t conduct research like that anymore.

TAPPE: Some of those behaviors, interestingly enough, helped bring HIV into the
heterosexual community. Because a man is bisexual, his wife doesn’t know it, he
brings home the disease. And that is still going on.

KOTARBA: I can think of at least two cases now of women who had that experience.
They caught HIV from their husbands. That would have been a whole great
study. I know people have examined the bisexual phenomenon since, but we
couldn’t get him to go into that direction. We did, however, hear those stories.

Usually a woman is like, “All of a sudden you’ve got AIDS out of
nowhere.” It was destroying marriages. They’ve got kids and all that they’re
destroying. Their husbands are out leading two lives. It still happens. It was
much more dangerous back then.

TAPPE: I’d like to wrap this up with trying to gather some thoughts from you about
what’s going on now several decades beyond the initial AIDS crisis. Medication
has changed drastically to the point that we have thousands of long-term
survivors. We have medication that people can take prior to and after sexual
encounters. In some populations, HIV infection is still on the rise. Gay and
bisexual men still account for the majority of new infections. In talking with
different people in the community, I’ve learned that a number of people of the
younger generation view the HIV virus now as more of a chronic-illness nuisance
to be treated like diabetes.

As a generalization, I wonder if you might have some insight into
society’s current view towards HIV, the infection rates, and sexual activities, and
do you have any particular advice for persons working on the front lines of HIV education and prevention? It’s a different world now.

KOTARBA: Very different. My fear is that AIDS is going underground. It seems like you read less and see less and hear less about AIDS now than before, and I think there are good reasons for that, given just the almost miraculous advancements in science for treatment of AIDS, prevention of AIDS too, so it has become more or less a chronic disease.

Now, is it just like other chronic diseases? Maybe, maybe not. The care for it is still pretty severe. You need some pretty heavy-duty medications for that. Overall, the medical advances have been great. The bad thing is that I hate to see something disappear, because it’s still there. It may not be in people’s attention but the risk is still there. My hope is that in terms of public health instruction, AIDS remains a topic to discuss with young people so they are aware of it.

I think there are some other really positive features of the communities that have been at high risk for AIDS that are worth noting, one of which is the increase — and I notice this anecdotally in my life, my work with young people at school and other places — the increase of monogamous relationships among young men. Young gay men routinely again — and this is in my world — routinely talk about having a partner, have a fiancé, having a husband. I think that’s one of the major factors that’s going to help in the reduction of the AIDS epidemic, is encouraging people to commit to monogamous relationships. That sounds very conservative. I know that. If I said that 25 years ago, that would have been a very conservative statement.

But point of fact is, from a public health perspective, when people have
monogamous relationships, they live better in so many ways, health and otherwise. When I see that among the young gay people I know and work with and teach, I think that’s just great. That’s worth celebrating. It helps you in so many ways so I think that’s a really good movement.

Again, the medications are getting to be so good now, although still pretty expensive, that as a chronic disease, people don’t have to let their AIDS rule their lives. Used to be, 25 years ago, if you had AIDS, that was what we call a master status in sociology. That was all you are. That’s all people needed to know about you to close the book on you.

Now, I don’t know. Who knows? Who cares? Who knows who has AIDS anymore? Which is good, because the stigma becomes less of a problem. Feeding into that, I think, is this overall more general acceptance of the gay/lesbian world to more general society.

I talk with my graduate assistant, gay young man, great young kid, beautiful young boy. Smart. We talk about one of our favorite programs. That’s RuPaul’s Drag Race on TV. He loves it. I love it. We talk about it. The way we talk about it is like it’s not like, “Well, as a gay guy, this is what I see,” “Well, as a straight guy.” We talk about it in ways that are comprehensible to both, to each other, and I think that’s the way culture is moving on those kinds of things.

Movies made about Elton John. The movie made about Queen that was out. It’s not so much the need to celebrate gayness, per se. We’re past that. It’s just simply saying that’s the way it is. If you want to understand these gay people, you’ve just got to understand, then, what’s it like to be gay as part of their life. That’s all it is. I think that was one of the really powerful aspects of the
movie about Queen. The gay aspect of that was downplayed a lot. Of course, there’s criticism of that. But that’s only one dimension of that musical group.

The proportionality of one’s lifestyle preferences is getting increasingly realistic and partial. And it’s great.

On CNN, *Anderson Cooper 360°*, he’s gay. So what? What’s the point? That’s where I think the culture is going. I’m very optimistic that way. But you can’t forget the risks, not just of a gay lifestyle, but anybody’s lifestyle.

Our other concern at the university is, are all kids using condoms? We don’t know. If they’re not worried about things like hepatitis or —

TAPPE: And there are other diseases that are preventable with the use of a condom.

KOTARBA: There you go. We just have to reinforce the fact that life is dangerous if you don’t take care of yourself, but that message applies to everybody, which is the way it should be. I’m very optimistic about how all that is going.

TAPPE: Thank you so very much. I appreciate it.

KOTARBA: I’d like to mention one more thing. There was a Dr. Didier Piot. I want to mention this. He was the major figure over at Park Plaza when they first started up their HIV unit. He had a reputation for probably being the first person to diagnose an AIDS case in Houston, and he treated tons of patients there.

When I was working with Diane Ragsdale and the TWU crew on our work over there at the AIDS unit, I got a request from the woman who was our liaison with Park Plaza. She said, “They want to do something nice for Didier because he’s not only been a leader in AIDS, but he also brings a lot of patients in, and he’s a good doc. We would like to do something.” She asked me because being an ethnographer, I’m the writer in the crew. She said, “We’d like to have maybe
a little booklet on him, on his biography and things, and we’d like you to do this.”

I said, “It sounds like a plan.”

Of course, when a hospital deals with a fancy doc like that, everything is top shelf. This is not sociology. We had a representative from Park Plaza. I was there. I had a graduate student help me out, be my scribe, and we would hold these interviews over at Dr. Piot’s apartment. That big, tall building in the middle of Hermann Park. He’s got an apartment there that looks both all the way north and all the way south.

I conducted a very intense interview with him. We’d talk for about an hour. We did that perhaps for or five times. We talked about his career and his life and what it’s like to work in the HIV/AIDS unit at Park Plaza. There were times when Dr. Piot actually broke down in tears — I’m not divulging anything, because this is a good thing about him — about how difficult it is to be working with all these young men, one after another dying, and there’s nothing you can do about it.

He explained, of course, those early days when the doctors at Park Plaza would experiment with almost anything. Even some of the drugs used to treat malaria, they were given to the AIDS patients because it dealt with fever, those kinds of things. It was really difficult for him to do this work and it was taking its toll on him, but he never said no to a patient and he never said no because someone didn’t have money. He would just treat them and do all he could and hold their hand.

So I wrote this biography. It was a gift to him. Park Plaza elegantly printed and bound this story. After every interview, we ended up going to one of
those fancy restaurants in the Montrose and we used to have a bottle of Dom Perignon waiting for us. Our whole little crew would get together. It was really nice for Park Plaza to do that kind of thing. He was quite the guy.

I recall a few other research-related experiences that have remained with me through the years. Between my community-oriented NIDA-supported ethnographic research in the 1980s and my hospital and hospice-based quality of life studies in the 1990s, I gathered media attention for my original work on HIV/AIDS. I was quoted in an article on AIDS appearing in *Cosmopolitan* magazine in 1991. In 1992, Mr. Bob Guccioni, Jr., cited me extensively in his regular column in *SPIN* magazine on the AIDS epidemic. In the following year, 1993, Mr. Guccioni invited me to serve on a select panel at the South by Southwest Music Conference on “AIDS and the Music Industry.” The panel turned out to be one of the most memorable of my life. Our panel consisted of a social worker, a record executive, a physician, an AIDS activist, a young man living with AIDS, and me. We were all enthralled by the young man living with AIDS whose accounts of his hopes, fears, crises, and difficulties brought a layer of everyday life reality to our discussion of the AIDS epidemic.

TAPPE: You’ve had a very interesting and extensive professional career. Tell me what you’re doing now.

KOTARBA: I’m doing a couple of things now in terms of research. In general, my work is in the sociology of culture. In the sociology of culture, I’m spending a lot of time looking at music, people’s music experiences, not related directly to anything medical except we’re working on a project with people with dementia and what it’s like to have dementia and still have music in your life. It’s very
tough to study something like that because those people don’t sit there and talk about rock and roll. But we’re very interested in the way music is presented to them by the people who are caretakers. That’s one study.

I keep up with my medical sociology, but I increasingly study the organizational dimensions of healthcare research, following up on the processes I was talking about at Park Plaza Hospital or the hospice, McAdory House.

My research on the social dimension of HIV/AIDS generated interest in women athletes, professional athletes especially, and the kind of healthcare they get, or injury care, which might be the case. The point is, I’m kind of begging the obvious by saying that in comparison to men, women’s healthcare is not nearly as good because as workers, they’re not as valuable as the male athletes.

TAPPE: That’s right. They don’t bring in the same kind of money, they don’t get paid the same.

KOTARBA: Exactly. Don’t bring in the same kind of money. When they get good care, ironically enough, it tends to be provided in a very informal, sometimes voluntary, basis by whom? Other women. For a while, there was a professional women’s football team, in Houston. I remember going there for tryouts and training and practice, and it was just fabulous to see how this team was operating, but during games especially, the sidelines were loaded with other women, who tended to be nurses, physical therapists, and physicians who were there to help out with other women on a volunteer basis. It was the highest quality on-site care I’ve ever seen during sports, better than men get. The problem is, of course, that if anything became a serious injury or something that required ongoing care, the women would have to back off and get back into the coverage they have at work
or whatever other medical care they might have.

TAPPE: The formal care.

KOTARBA: The formal care. But they have all these women there. I said, “What are you people doing here?” I mean, the word “sisterhood” would come out on occasion back in the day. I’d say, “That’s pretty cool.” But they had like high-quality, all specialties, doctors out there, even though they generally didn’t have too many injuries. They were in pretty good shape. But that was interesting, so it kept me looking at these issues of women’s health and healthcare. What you get is tying into my work with dementia in elderly types because they were talking about women outliving men, and then they were going to be the predominant population there. I sort of throw that out to what we’re going.

TAPPE: Do you plan on continuing your work for a while?

KOTARBA: Yes, I do. It’s too much fun to do, and in my kind of work, I can continue to do it. I like bringing grants in. When I moved to Texas State to set up my research center, I brought in about $250,000 grant money, which was kind of nice.

TAPPE: That’s a big deal.

KOTARBA: Yes, and not always in areas of my interest. That’s what happens when you’re running a center. It was nice to have resources to support students, and my topics of interest are just plain fun to work on. And students, if they’re interested in it, they’re always there to help out and get their thesis done.

I’m 72 now. I don’t know. I would like to put another year or two in before I hang them up.

TAPPE: Well, there’s no need to put a number on it. Play it by ear.
KOTARBA: It’s not the kind of job you necessarily want to escape.

TAPPE: Certainly, you don’t. Thank you, Dr. Kotarba. Thank you very much.

[END OF AUDIO PART 4]

[INTERVIEW CONCLUDED]

* * * * *