

THE
OH
PROJECT | Oral Histories
of HIV / AIDS
in Houston,
Harris County,
and Southeast Texas

*To collect, preserve and make available the experiences
of people impacted by the HIV/AIDS epidemic in
Houston, Harris County, and Southeast Texas*

Oral History # 035

An Interview With
Chella Ware

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AN INTERVIEW WITH CHELLA WARE

LYNN SCHWARTZENBURG: This is Lynn Schwartzenburg interviewing Chella Ware for The oH Project. The interview is taking place August 8, 2018, in Houston, Texas. I am interviewing Ms. Ware to document her recollections concerning the response to HIV/AIDS in Houston.

Thank you for doing this, and welcome.

CHELLA WARE: Oh, thanks, Lynn. I'm just honored.

LYNN SCHWARTZENBURG: Let's start at the beginning. Tell me, when and where were you born?

CHELLA WARE: I was born in Plainview, Texas. I call it the Panhandle, some people call it West Texas, but it's way far north, by Lubbock, where Texas Tech is. We just lived there shortly, and then I think we moved to Bay City right after that. I'm the second daughter, middle child, so I have all that middle-child syndrome, and then I have a younger brother that died of AIDS, and a younger sister.

LYNN SCHWARTZENBURG: Tell me about your parents.

CHELLA WARE: That's difficult. My mom was from Colorado, and she married my dad, who was in the service. He was in the Air Force. Toddy was his nickname. My mother's nickname was Jean. My dad was just gorgeous. He looked like Clark Gable, just beautiful. Looking back, I think he was gay. I really think he was gay. He wasn't happy in the marriage.

I didn't have a pleasant childhood. My happy memories are in the summer, when we used to go to Colorado, to my grandparents' farm and ranch,

and I could harass the chickens and the cows. I'm sure they were so glad when I left. They probably had to give them all Valium when I left. I would say I would pick eggs. I'd run into the chicken coop and be messing with the chickens like every five minutes. They probably didn't lay eggs for two weeks. That was my good memory of the summer.

SCHWARTZENBURG: What did your father do for a living?

WARE: He was a court reporter. After the service, he was a court reporter. He traveled some, and that's in 1959. It's conflicting. My sisters and I can't ever agree, and I don't guess Mother did either, because I thought he had a heart attack and had a wreck late one evening, but my sister said no, he just had a wreck and died.

He left my mother at 36 years old with four children. She had no visible means of support. She had never worked. She married my stepfather shortly, about a year, a little more than a year after that, and then that's when we moved to Houston.

SCHWARTZENBURG: She met him in Plainview?

WARE: Met him in Bay City, when we moved to Bay City. He was an alcoholic, but he was also a liquor salesman. That always makes me laugh, too. It would be like a heroin addict working in the poppy fields or something.

SCHWARTZENBURG: When did you move to Houston?

WARE: In 1960, I believe.

SCHWARTZENBURG: What age were you, about?

WARE: I was born in 1950, so I was 10 years old. Daddy died right before my ninth birthday. It was a little more than a year later Mother remarried and we moved to Houston, to Westbury, and I lived there. My claim to fame of moving is moving

to The Heights in 1989, and that's the farthest I've been from home. Big baby.

SCHWARTZENBURG: That's a lot of change for a 10-year-old. Father dying, mother remarrying, moving, uprooting. What was school like for you? Did you get along with your peers?

WARE: Yeah, I think. I was a clown. Of course, back in the 1950s, no one knew what to do with grief, with their grief, with other people's grief, and we really weren't encouraged to grieve.

This story just came to me. I went to Catholic school, and my father died in June. School started in September, and I think I was in fourth grade, and there was a father-daughter dance, and the girls all were writing letters to their fathers to invite them. Well, I just laid my head on my desk and started bawling because my dad was dead, and the nun was absolutely paralyzed as to what to do with me. She didn't comfort me. It was almost like I was shamed.

SCHWARTZENBURG: For having grief.

WARE: Yeah, for crying and not having a father, like that was —

SCHWARTZENBURG: It was your fault.

WARE: Yeah, how dare I. Even that was just such an odd experience. I think that's probably why death and dying and grief fascinates me so much as an adult. With the AIDS patients, because I know one of the questions, it took me about 20 years to fully grieve all their deaths, and I thought I was up on it. Oh, I can do this. I've got this. Yeah, right.

SCHWARTZENBURG: What did you want to be when you grew up?

WARE: Had no idea. I was not encouraged to do anything. I didn't have any aspirations. I remember coming home, I think my late junior year, maybe senior

year, and all the kids in school were getting acceptance letters to go to college, and I came home and I said, “I think I want to go to Stephen F. Austin.”

Well, my parents just kind of exploded. “What do you mean?” Of course they didn’t have the money. Instead of saying that, it was like making me feel like I was so stupid, how do I dare think I could get into college?

After I was married, the third marriage, if you want to be precise — let’s see, I was 25 — I went to nursing school, and that was because my husband almost blew himself up with making his own bullets, and he was using black — oh, I can’t think what it was. He was trying to make sparklers for the kids. It was, I think, New Year’s Eve, and he put it out on the sidewalk and held the can of — it’s black powder, is what it is — and the little trickle of the black powder caught on fire, and the can exploded in his face.

I took him to Sharpstown Hospital. I thought that was the best one to go to. I was nursing him. Both his hands were burned. He couldn’t do anything, eat or anything. I thought, “I can do this. I can be a nurse.” I really give him credit. I don’t give him credit for much, but I really give him credit for getting me to community college to take my basics and go to nursing school.

SCHWARTZENBURG: How many kids do you have?

WARE: I have two, and he adopted them. I had Kelli when I was 18 and Jason when I was 19, and I was pregnant when I got married. I’m just now, or the last few years, reconciling with the baby daddy, and it’s a neat relationship. I’m very blessed for that, but it took us about 40 years to get to that place.

SCHWARTZENBURG: Where did you go to nursing school?

WARE: Went to San Jacinto College in Pasadena, and then later on went to UTMB

[University of Texas Medical Branch] to get my bachelor's.

SCHWARTZENBURG: That was a two-year degree —

WARE: Yeah, associate's degree. And hard, whew. That was a hard two years.

SCHWARTZENBURG: What made it hard?

WARE: Because it's so compacted into two years, and you're doing your theory and then your clinicals. We were sometimes 10:00, 11:00, 12:00 o'clock at midnight working at the VA [Veterans Administration] or somewhere just to get our clinical hours, and then back early in the morning to do theory. It was just hard. I really had to buckle down. I'm a good "B" student. I'm not an "A" student. The chemistry and the microbiology and all of that was kind of —

SCHWARTZENBURG: And the exhaustion, it sounds like.

So you were out of school, what year is that?

WARE: 1977.

SCHWARTZENBURG: Did you go work right away in nursing?

WARE: I did PRN. In fact, it was Spring Branch Hospital, which is no longer here either, and then got a job at Great Southern Life Insurance Company as an occupational health nurse.

SCHWARTZENBURG: What does an occupational health nurse do?

WARE: They really didn't need one there, and I'm not sure why they had that position. For emergencies, because they had a big printing, you know, with the huge, huge equipment down in the basement, in case somebody got hurt. But it was kind of trying to keep people — you know, if I could give them aspirin or Tylenol instead of them going home. I gave flu shots and took blood pressures and wandered around. I did breast self-exam training and blood pressure monitoring and

training and that kind of thing.

SCHWARTZENBURG: So almost community health, but on the job.

WARE: Right, right.

SCHWARTZENBURG: Then what did you do after that?

WARE: That's when I first met my gay friends at Great Southern, which I have to this day, the ones that haven't died. I said, "Oh, I'm cool. My brother is gay. I can go out," so I would go out with my nursing uniform on to the lesbian bars, Jesus. "I'm here to do breast self-exams."

SCHWARTZENBURG: "Let me teach you, honey."

WARE: I met a woman that hit on me, and I just thought that was the greatest, but it was kind of chic then because I could say I was bisexual. That was the cool thing, because I was still married. But after that is when I went to work for M.D. Anderson. I was in the process of getting a divorce, moving out for the first time and being by myself for the first time, and went to work in the OR [operating room] at M.D. Anderson in 1982.

SCHWARTZENBURG: It was at M.D. Anderson that you encountered your first patient with AIDS; is that right?

WARE: Yeah. That must have been in 1983 or early 1984. There was just kind of a buzz in the operating room about patients, and I didn't really understand kind of what was going on because nobody knew exactly what it was, but we were getting in men with Kaposi's sarcoma, and that's when they were doing the bronchoscopies because that was the only way they could diagnose the pneumocystis pneumonia, and then they'd bring them back upstairs, and a day later they'd die.

Anyway, I just happened to walk by a room, and they had just finished a bronchoscopy, and there was a young man lying on the operating table. I remember looking at the staff, and they're throwing Clorox and they're scared to death, and I looked at him, and his eyes, it was like a wounded bird. He couldn't talk, but he was scared to death. So I just walked up to him and held his hand, I don't even know if I said anything to him, and I thought, "I can do this. I'm not afraid. I can work with these people." I didn't even know who "these people" were, but I knew they were gay, and it's like I have no fear of that.

SCHWARTZENBURG: Did you have universal precautions at that time?

WARE: Oh, no.

SCHWARTZENBURG: The Clorox was just kind of an afterthought? "We'll just kill whatever"?

WARE: Right, they thought that was the best they had, so they would use it. I think it probably worked, but you normally wait until the poor patient is out of the room before. I mean, you could hardly breathe.

SCHWARTZENBURG: So the shame and the fear that that man had.

WARE: Yeah, it was. And the staff, too, they were scared to death, but they had no respect for the poor little patient lying on the table.

SCHWARTZENBURG: Were you able to make a conscious decision, "I can do this. I can help these people, whoever these people are. How do I get out of the operating room and go to where they are?" Was there an avenue for that right away?

WARE: Well, there was, kind of one of those God things, spiritual things. I called, it was either Station 10 or 12. It doesn't really matter. It just so happened that one

of the nurses, one of the first nurses that worked with Dr. Mansell, was moving, and so they were needing another nurse. It's like, "Yes, I can do this," so I went and interviewed and got the position.

SCHWARTZENBURG: That was a unit dedicated only to patients with AIDS?

WARE: Right. I think we were calling it ARC [AIDS-related complex]. I don't know why I can't remember, because it was, I think, even before the HTLV-3 and way before the AIDS nomenclature, if that's the right word, came out, but they were severely immunocompromised, and a lot of them had the Kaposi's sarcoma, which you rarely see anymore. That's one reason they got into M.D. Anderson, is the Kaposi's sarcoma, it's a cancer.

SCHWARTZENBURG: I was going to ask, why M.D. Anderson and why Dr. Mansell?

WARE: Well, I don't know. I don't remember. He was in preventive medicine, and I guess I never asked him why. I think he just kind of fell into the position. I don't know that he had much — and Guy Newell, Dr. Newell, was there. He would kind of sporadically come in and out. He kind of had his own issues going on.

SCHWARTZENBURG: When people started showing up with KS, would they intermingle throughout M.D. Anderson?

WARE: No. They kept them with Dr. Mansell. I guess I never asked, or I don't know, because there was about a year that that clinic went on before I came in, and I don't know if I don't have any memory or I don't know, but he's the one that — and probably because he was not afraid of the gay patients, and they were all coming in. It was a cancer diagnosis, and that's the only way they got their foot in the door. But then after that, almost all the immunocompromised patients came there, with a KS diagnosis or not, because Dr. Mansell was seeing them. At the

time, there really wasn't anywhere for them to go. I think then Park Plaza stepped up, and they started seeing the patients. Of course, the old Jeff Davis and Ben Taub.

SCHWARTZENBURG: What was it like to work there on that station?

WARE: I've said many times, it was the best of times and it was the worst of times. Of course, I've got that typical caretaking, so I'm the mother to all of them, and they were there all day long, all day long, and I befriended almost all of them.

SCHWARTZENBURG: So this was more an outpatient clinic than inpatient?

WARE: Yes, right. Now, they had inpatient on the ninth floor. I don't know if you remember Marva Jeane Finley or hearing about her. She's passed away now, but she was the head nurse. They just kind of dumped them on the ninth floor. They didn't ask to have those patients, and the nurses really stepped up, but boy, was that hard because they were so sick; you know, the diarrhea that was just uncontrollable from the Cryptosporidium. It was brutal. It was brutal. They're the ones, you know, that's where they died. We would go up and visit after clinic, but they took care of them 24/7 [24 hours a day, seven days a week].

SCHWARTZENBURG: People would come to the clinic because they were having symptoms that they couldn't manage at home, or they just needed a checkup from Dr. Mansell?

WARE: Well, they needed a diagnosis. Again, I can't remember what test we were doing. If it was just symptom management, you know, they had all the symptoms. At the time, and I'm not trying to be homophobic, but most all of them were gay. I mean, that was the population in Houston at the time.

SCHWARTZENBURG: About how many patients would be in the clinic a day, do you

think? What was your capacity? What was a day like?

WARE: I'd say 20. I'd say 20, sometimes less. It had to be less, because we would see them in the morning, now that I'm thinking about it. We would probably see 10 patients, and there were so many new ones coming in, and that really took up a lot of Dr. Mansell's time. Then Dr. Rios, Adan Rios, was hired. Then Gary Brewton was hired, because it was just overwhelming. Dr. Mansell couldn't take care of all of them. Then at noon, we'd go up and make rounds.

Now, he wasn't writing orders. We were just checking on the patients and saying, "Hey," because they knew us and we knew the families. That was hard because sometimes we would be up there and the patient was dying or had died. It was just an endless — I say we were just in the trenches. It was like being at war because you couldn't — we were just throwing medicine at them, and that was even before AZT [azidothymidine], so what we had, we were giving to them, but it wasn't doing any good.

Then we gave them interferon, and I think that killed them before because it was — oh, they would just go into these horrible chills and sweats and aches, but we were just trying whatever we had, and they just died and kept dying and kept dying.

SCHWARTZENBURG: Were there any survivors from that time, that you can recall?

WARE: One time years after I quit working there, one of the first women, she was a young woman, and she had gone out of town, I think to New York, with her hairdresser, and they got boozy and loaded and had sex, and she ended up contracting the virus, and I saw her years later. Now, whether she's still alive, but she was one of the longest-surviving. But no, they didn't. I mean, it was a death

sentence. They knew it and we knew it.

That was one of those stories about Dr. Mansell. I noticed, it finally dawned on me that sometimes either in the clinic or when we'd go upstairs, he would get real ugly with the patients. I said, "Dr. Mansell, why are you being so ugly? You didn't have to say that," and shortly after, the patient would die.

So when he started that, I would just go pieces because I knew the patient was dying and that was his defense, his cover, to kind of push away from the patient and get snarly and act like he didn't care, and it was like, "Oh, it's another one, uh-huh."

SCHWARTZENBURG: What did you do with that? How did you cope?

WARE: I just knew they were dying. You try to be as kind to them and spend as much time up on the floor or wherever because a lot of them didn't have family. Their families abandoned them, or their partners were scared or had already died.

SCHWARTZENBURG: Would they die in the clinic, or would they be admitted and be up on the floor?

WARE: No. They would be admitted, yeah. They would be admitted. We had one patient, he was the biggest seller of — what's the amyl nitrate? I mean, he made like bathtubs of it. He came in and died the same day, or maybe 24 hours, because he had waited. You know, they would wait. They were in denial, too. Their families didn't even know they were gay.

One of my other stories I always told, that they'd bring their families into the clinic, and as we're walking down the hall to put them in a room, they would whisper, "My family doesn't know I'm sick, and they don't know I'm gay."

It's like, "Welcome to a tour of M.D. Anderson." It's like, what do you

say? “Why do you think you’re here?” I wouldn’t say that out loud. I’m thinking. Then I would say, “The good news is, your child’s gay. The bad news is, they’re dying of AIDS.”

That’s kind of the way it was for the majority of the families. They would go home — I can’t remember his name, but he lived in Paris, Texas, and the family sent the obit or his sister sent the obit, and it said he died of leukemia, died at M.D. Anderson Hospital of leukemia. That’s the way they coped, especially in the small towns, because it was a shame-based kind of disease at that point. I don’t know if that’s the right word to use, but it was, for the families, not the patients.

SCHWARTZENBURG: It had stigma attached.

WARE: Yes, for sure. If I can keep telling stories.

SCHWARTZENBURG: Yes.

WARE: Up on nine, we were making rounds, and this young man, happened to be African American, he was a pastor, and the family had no idea he was gay, didn’t know he had AIDS, he’s up on the ninth floor, and when we started to walk into the unit, he passed away, and the wailing out of that room. Of course, I grew up in the Catholic Church, and we’re very quiet. You know, little tears, little tears. We don’t emote. I had to leave. I thought if I don’t leave, I’m going to go to my knees and just curl up in a ball. I had never heard such pain and agony in my life. It was just so unnerving.

SCHWARTZENBURG: How did the rest of M.D. Anderson react or deal with your station and then the ninth floor?

WARE: I think we were pariahs. I really do. The issue, too, was probably, and I’m

guessing, 75, 80, maybe even 90 percent of the patients were indigent. Very few of the patients had — if they did, they had good jobs and good insurance, but the majority of them did not, so it was really taking a toll. I mean, they were Texas citizens. But especially if they didn't have KS, it's like why are they here, and why are we spending so much money on them?

SCHWARTZENBURG: Right, they were expensive.

WARE: Yeah. That was a real interesting — and that's one of the reasons, I think, that UT [University of Texas], you know, M.D. Anderson, they were so thrilled that the patients, when the hospital, the AIDS hospital — they were so glad to get rid of them, they were doing a happy dance.

I kept telling the people at the new hospital, I said, “So many of them are indigent. How do you think you're going to make money? You're a for-profit organization.”

They just acted like I had 12 heads and didn't know what I was talking about. What, it lasted a year, year and a half, and went bankrupt because the patients didn't have insurance. “Really?”

Tom Caleb, I don't know if you remember him, called me and said, “Guess what? The hospital is closing because they have too many indigent patients, and you said that a year and a half ago.”

I said, “Thank you, Tom, for recognizing my brilliance. No one else did.”

I was trying to warn them. “If you think you're going to be making money, you're crazy.”

SCHWARTZENBURG: I heard also that AMI [American Medical International, Inc.] thought it would be like Park Plaza, and everybody is admitted and stays for three

or four months, and there's insurance paying for everything. But Dr. Mansell came with the clinic model, so there were no admissions. It was all clinic work, and they were like, "Oh, well, that doesn't make any money, just having a clinic. You need to have them inpatient so you can make the big bucks."

WARE: I think they had inpatient. Didn't they have inpatient?

SCHWARTZENBURG: They did.

WARE: Or small.

SCHWARTZENBURG: But Mansell preferred the outpatient model.

WARE: Right.

SCHWARTZENBURG: And it was so far out that it wasn't easy to get to for outpatient, so there were a lot of problems.

They all go. You, I guess seeing handwriting on the wall that it wouldn't really make it, not believing that that new hospital would make it, is that why you just stayed at M.D. Anderson?

WARE: Right.

SCHWARTZENBURG: What did you do at M.D. Anderson after that?

WARE: I was in neuropsychiatry, and it just happened that Frank Fernandez was one of the few doctors that he would — we had a weekly meeting with people in the town and the county that would come, social workers from different hospitals and stuff that treated the patients, and just kind of have a pow wow about what was going on — Gary Treese was a social worker, I don't know if you remember him, he was a neat man — just so they could kind of keep in the loop and we could, too, if there was anything new coming down the pipe. I worked with him, so I got to go to the hospital. That was hard.

Gary Treese told me, he said, “You’re not going to know grief until you quit working with the patients.”

“Oh, Gary, pish.”

Well, I missed them so much. I grieved. Grieved, grieved, grieved. Every time I’d go there, I’d walk in crying, I’d leave crying. It was just a calling for me, but financially I just couldn’t not have a job, and I could just see that coming, and everybody at the institute lost their jobs. Then Peter went on. I guess he went back to Europe. I’m not sure.

SCHWARTZENBURG: Who else was part of the HIV units at M.D. Anderson? There’s Peter Mansell. You said Adan Rios, Gary Brewton. What about Sue Cooper?

WARE: She was a social worker. She kind of got in with, I don’t know if it was Jon Lindsay of the county, but she was doing a lot of fundraising, and she went as, I guess, the social worker, but she might have had like a VP [vice president] title by then, because she was really one of the ones spearheading the hospital.

SCHWARTZENBURG: She was a controversial person. What was your experience with her?

WARE: I thought Sue and I were very close at the hospital, at M.D. Anderson, and she was very kind and very supportive when the patients were dying, because I was always blubbing about somebody dying. But when she went to the hospital, she had no more need for me, is kind of how it felt, and I rarely, rarely talked to her, rarely had anything to do with her, and it just seemed like she just kind of changed and her focus changed and it was kind of all about fundraising and getting more money and kind of being in the who’s who of AIDS treatment and AIDS. It hurt my feelings, I mean, it did. It just kind of is what it is. In fact,

didn't Sue pass away? Didn't she? Didn't somebody tell me?

SCHWARTZENBURG: Yeah.

WARE: And you don't know what it was? Because she had melanoma at one time, and I was always wondering if maybe that recurred. She had a wide resection.

SCHWARTZENBURG: I'm not sure.

WARE: I guess we can talk about that since she's gone. Talk about HIPAA [Healthcare Insurance Portability and Accountability Act], I'll just tell everybody, tell you everybody's business.

SCHWARTZENBURG: We were talking about how the rest of the hospital reacted to you, and you mentioned one incident in an elevator while you were at M.D. Anderson.

WARE: That was after I left the OR, and I ran into Dr. Suku. He had a name. We just call him Dr. Suku. He said, "Chella, I haven't seen you. Where have you been?"

I said, "I'm working with Dr. Mansell down in Station 12."

He started backing up in the elevator like I was irradiating radiation or something, and it just made me laugh. I mean, here's this brilliant anesthesiologist and just acting so ignorant, and it made me laugh. It was sad. It was early on, so nobody knew. Everybody was kind of scared. That was one of the things I think I brought up you were asking about. Of course, we had no universal precautions, and were giving injections in the clinic of whatever drug we could get ahold of, and by the grace of God, we had the alcohol swab sticks, which are what, about two and a half, three inches long? We would use that to wipe the skin and also use it to stop the bleeding. If we had had the pledgets, the little alcohol pledgets, we would have had blood all over us all the time.

SCHWARTZENBURG: Right, and no gloves.

WARE: And no gloves. So it was like wow, you know, those little angels floating around the clinic for us.

SCHWARTZENBURG: Taking care of the caregivers.

WARE: Yeah. Really, I think that's what that weekly meeting was, trying to take care of us, but you didn't have time. I mean, they were just dying, dying, dying. I probably went to one funeral or memorial service a week, I bet. In three years, I probably lost 200 patients. I mean, I quit counting at 100 or 150. It was like I can't keep doing this. It just is what it is. You would know them and their families because you spent so much time in the clinic with them.

SCHWARTZENBURG: And at barbecues at home.

WARE: Yes, I brought stray — people bring stray kitties and puppies home. I bring stray patients with AIDS home. Two of them. Dick Schroeder lived with Vickie and I, my partner at the time, for about six months, I guess. He was a neat kid. And then another. Bill Yates is one from Dallas, and he was in middle management at American Airlines, and he begged me to marry him before he died so I could get his spousal airline privileges.

SCHWARTZENBURG: Get miles.

WARE: Yeah, and miles. I said, "Bill, I would love to do that. That would be so cool. But I can't do that to your family. You own a home. That would all be tied up in court."

One time when his mom came down, we had a big barbecue and had her over for barbecue. Not only that, I got my whole family involved with the patients. My kids knew them. My family knew them. I had cousins out in Alvin

that invited us over. I took Dick out there for a swim party. So when they died, my whole family is grieving them. First of all, they're not used to being around. For me, it's just an everyday — you know, you have patients, you love on them, and then they leave, they die, and then another one or 10 come in, and you start all over again. Just no boundaries, none whatsoever.

[END OF AUDIO PART 1]

SCHWARTZENBURG: How many years were you a part of that clinic?

WARE: About two, and then a year at the institute. I would go once a week for their meetings and stuff. It wasn't much time, but there was a whole lot of going on in that short amount of time.

SCHWARTZENBURG: And a lot of loss.

WARE: You didn't have time to grieve. You really didn't. You'd just have to suck it up and take care of the next patient.

SCHWARTZENBURG: What would it be like at the funerals, for you? Did you steel it off, or did you just kind of —



AIDS Quilt Display, Washington, DC. 1995
L to R: Kelli Ware, Chella Ware, unknown male, Vicki Brim, Will Heimbach, Patti Diamond, Peter Doodeheefver.,

WARE: No. I could boo-hoo and get sad. I don't remember the circumstances. I think I was at a — it wasn't a retreat. It was a women's something or other, and we were doing a silent meditation, you know, lying on the floor and thinking about things

that might bother you. And that's 20 years after, it hit me, and I just kind of started seeing all the patients with AIDS, or all the patients that had died. I even thought about doing a quilt, but I couldn't remember all of their names and the quilt would be the size of a football field. I think I was able to finally really grieve their loss, and I cried and I cried and I cried. I honestly didn't think I was going to stop crying. I still think of something or run across something and think about it.

Of course, having a brother that died of AIDS-related disease. The sad thing to me with that was, I wasn't working with patients with AIDS then, and he had no insurance, and I had no way to get him help. Jane Nelson went through the same thing with her brother, when you would think for some stupid reason, well, somebody owes me something. Help me. I need help. I helped all these years. Now I need help. My brother needs help. He was in Fort Worth at — I'd think I would forget that hospital. It was like Ben Taub.

SCHWARTZENBURG: The county hospital?

WARE: John Peter Smith, that was the name of it. It was wretched. It was just before AZT came out. My mother died about five or six years ago. Every day she would say, "Oh, if Larry could have just lived a little bit longer, he could have been on those medications," and she's right, but his little body was ravaged too by 1992 and he couldn't live any longer without — and I don't know. He never got AZT because he didn't have the money.

SCHWARTZENBURG: But AZT wasn't the cure.

WARE: Well, come to find out with that *Dallas Buyers Club*, we were giving them a gazillion more times the dosage than what they really should have had. There

were rumors in the clinic, too, that a couple of the patients — it was a blinded study — that they bought their way into getting the drug. Now, I don't know if that was true. I hope it wasn't. But I mean, people were desperate, and if they had the money, you know, I'd probably do the same thing, especially for a loved one. If I had the money when my brother was dying, I would have done anything for him. All I could do was make sure he was so drugged that he didn't feel any pain. Like I said, our family was in pain. Larry wasn't in pain. I had him comfortable.

SCHWARTZENBURG: Did he die in Fort Worth?

WARE: Uh-huh, he died at Mother's house. He was at her house, which was good.

That's what she wanted. She wanted him home. We had all the family and the AIDS volunteers. I always say I wish I had had a camera, like a security camera, for that whole week or 10 days to kind of see this wonderful ebb and flow of family and caregivers and love. It was an awesome, awesome experience, even though it was so painful, but there was so much love for him. We never left him alone. In fact, the first thing I did was crawl in bed with him and start singing to him, because my family had no idea, and I didn't think about it. They had never seen a dead body, much less a family member, and a young family member. So they'd kind of watch what I would do, and then they'd crawl in bed beside him and talk to him.

SCHWARTZENBURG: You were modeling behavior for them.

WARE: Yeah.

SCHWARTZENBURG: It almost sounds healing compared to all the other deaths you experienced.

WARE: Well, because some of them, I was the only person in the room with them when they died, holding their hands. Their family wouldn't — you know, they had bodies, I don't know what they ever did with them in the morgue, that their families wouldn't claim. I don't know if there's like a paupers' cemetery, I think there is, in Houston. I don't think they use that word anymore. Good Lord, dating myself. But I guess that's where they took the body and buried him.

SCHWARTZENBURG: Was there a typical — I'm sure not — but typical kind of family reaction? Or what were some examples of how families reacted to find out their son was gay, to find out that they were HIV positive, had AIDS, and then were dying? What were some of those experiences?

WARE: I think kind of what you would expect. They were just stunned at first and had no idea what to do with that information, and they would just kind of walk around in a daze the first couple of times they were in the clinic. Those that accepted their children — a lot of the men were only children. I mean, that was it. They were losing their only child, which was painful enough. If they were loving and accepting parents, you'd see them back in the clinic every time, every time. If not, you didn't see them again, the family, the parents. They wouldn't have anything to do with them. I think that's why I tried to be there for them. Sometimes the only thing I could do was get a blanket and a pillow because they were in the clinic for so long. That was it, but that was the most comforting thing I could do for them, and kind of a kind gesture to let them know that I cared about them. A pillow and a blanket, and that was it. That's all I could do.

SCHWARTZENBURG: Were your co-workers that were also in the clinic or up on the floor, were they of the same mind-set as you were in the caregiving role?

WARE: Peggy, and I can't think of her last name, she was in the clinic. She went to work in the OR, which I thought was funny. We kind of switched places. But Dr. Rios had his own nurse, and she just kind of didn't get it. That was just a job to her. She didn't really connect or want to connect, and maybe that was just her way of protecting herself.

On the ninth floor, it was a little different. They cared and they did their job, but that was not what they signed up to do, on the ninth floor. They were just given the patients to take care of, so it was tough. It was hard for them, but they did their jobs. I don't remember hearing of anybody quitting because of it, but it was just an 8- and 12-hour shift, but sick, sick patients, like the Cryptosporidium. They were losing liters and liters of stool, just, as I say, not very nice, but they just shit themselves to death. I mean, they really did. It was just horrendous. What a way to go.

SCHWARTZENBURG: Were there any other gay or lesbian nurses?

WARE: Not that I knew.

SCHWARTZENBURG: Were you out?

WARE: No, I was not out. Michael Wilson told Dr. Mansell, and I heard he got really mad that I didn't tell him, but I just — Vickie was my roommate, and that was just a time that I don't know why I was — maybe it was just that internalized homophobia, and I didn't look — I wasn't masculine, didn't have the short, little-boy haircut, so I could fit in any way I wanted to. I mean, I didn't care that he knew, but it surprised me that it made him mad. Maybe because he thought I didn't trust him enough to tell him. I don't know. Who knows but for Peter Mansell? Crazy man.

SCHWARTZENBURG: One family, didn't they, instead of going to the funeral, went and —

WARE: Yes, thank you for reminding me of that. Michael Wilson worked at M.D.

Anderson in preventive medicine, and he was one of the founders, and they called it the KS/AIDS Foundation at first. He was one of the founders. He and Richard, who was his partner at the time, broke up, and then Richard and Gary got together, and they bought a — well, Richard bought a home in The Heights, not too far from me.

When Richard died, we were all at the — there were not too many funeral homes that would take the patients with AIDS. The one downtown, this big, white building. I can't think of the name of it. Anyway, we waited for his parents, we waited for his parents, and we waited, and they were late. Well, come to find out they were late because they got a big U-Haul and backed it up to Richard's home, because Gary was not in a will, and emptied out that house, and Gary had no place to go. That was the damndest thing I ever saw in my life.

Of course, and then immediately Vickie and I went and got wills, not that we were going to die from AIDS, but it's like I don't want that happening to her or to me, to have a parent or somebody come in and strip your house. Talk about grieving. You would grieve the loss of your partner, and then you're homeless.

SCHWARTZENBURG: Insult to injury.

WARE: At the time, too, even if you had a will or living will, whatever, the family could step in and either take them off life support when the partner didn't want to, or mainly it was keeping them on life support when the partner and the patient had discussed that, "No, I do not want to be resuscitated." Well, then weeks and

weeks and weeks go by and they're still on the ventilator.

SCHWARTZENBURG: You talked about this being a calling for you. Tell me more about that. Is that something you realized at the time, and so this was a conscious decision, or is it something, reflecting back, that it feels like a calling?

WARE: I think it was just seeing that poor little guy on the stretcher in the OR just looking so pitiful and being treated so disrespectfully. I don't know if it was because I was a lesbian or just because I was a nurse and that's kind of how I treat people, but it's like I can do this. This doesn't scare me. I'm not frightened of it. I don't think I'm going to catch it. I'm not going to get it from anybody.

Too, with that, I went to Bering Care Center several years after that with patients with AIDS, but it was a totally, totally different group of patients with AIDS. Their primary issue was drugs and alcohol addiction and, "Oh, by the way, I'm HIV positive or hepatitis." HIV was not in the forefront. There, it was getting alcohol and getting drugs, and it was such a different group of people. It was difficult to work there. I guess maybe I just thought that Station 12 would be kind of recreated at the Bering Care Center. It would kind of be the same loving, caring patients and loving, caring staff, and it didn't happen. I mean, the staff was caring. I can't say that.

SCHWARTZENBURG: How long were you there?

WARE: A couple of years. But like I'd bring books in, some nice coffee table books just like home for the guys to read during the day. Well, they'd steal them and take them to Half Price Books and sell them and get money and go buy whatever. It just had totally changed, because we had — not that it makes any difference, but Perry Ellis and his partner were there at MD Anderson. An Austin statesman

came down to be treated, not that you have to be a professional to be treated or respected, but they would have done anything to take care of themselves if they had the drugs and whatever. We just didn't happen to have them, and at Bering Care Center — you know, Thomas Street was throwing drugs at them to help them. Well, they just could give a shit, most of them. If they miss their drugs, okay. Or they probably sold them, if I had to guess.

SCHWARTZENBURG: Because their primary issue was addiction.

WARE: It was addiction. Drugs and alcohol. It was a real eye-opener to me, plus it didn't pay very well, so I mean, that's one reason that I left. They'd work you like a dog. Of course, it's nonprofit.

SCHWARTZENBURG: When were you involved in research, and what was that like, related to HIV?

WARE: Well, I was a research nurse. That was my first research. I've been in research for 30 years now. Knowing what we did back then — I mean, Dr. Mansell threw the protocol at me and said, "Okay. Read this. Now you're a research nurse," like gave me the sign of the cross.

SCHWARTZENBURG: You're a research nurse.

WARE: I didn't know what the hell I was doing. I guess we got informed consents on the patients. I don't remember. I guess Dr. Mansell did. I didn't know that you were supposed to do that. I was just going about the business of taking care of the patients and trying to make them as comfortable and love on them, really.

SCHWARTZENBURG: Right, and there was research also going on.

WARE: Right, that was just nothing, but we were doing. That's all we had at the time. I think Peter got informed consent. I didn't. I don't remember that.

SCHWARTZENBURG: Being that you were doing so much research, would that give you first dibs on any new drugs to try or any new protocol?

WARE: Oh, absolutely, absolutely. It's just back then, none of them worked. I mean, they didn't.

SCHWARTZENBURG: What were some of the drugs that you were studying? Do you remember?

WARE: The only one that I remember is glucan, and it was kind of a milky thing, and it was a doctor friend of Dr. Mansell's out of New Orleans, and that was something. But like Dr. Mansell always said in his lectures, it's an immune deficiency, and his analogy was like a bucket with a hole in it. You can treat the infections, you can treat the pneumocystis, you can try to treat the Cryptosporidium, but it's like pouring water into a bucket and it's just coming out the bottom because there's nothing to treat the immune system. It is damaged, very, very damaged. I think he knew at the time that there had to be probably more than one drug. The cocktails were three. I don't know what they are now. I'm so out of the loop, it may be down to just one pill now. What they've done with hepatitis, I mean, that's just miraculous to me that it's no longer a —

SCHWARTZENBURG: A death sentence.

WARE: Yeah, a chronic disease, because a lot of them had hepatitis as well. Yeah, glucan, I don't know why that sticks in my head. I can't remember. But the AZT was the last drug I worked on.

Oh, interferon, yeah, we used interferon. I'm afraid that probably hastened their death, it was so hard on them. Mercy. They'd get psychotic, which a lot of people do. I know they have newer drugs, which is what I'm

working on, but that's all they had at the time for melanoma, and they would give that, and that just was crazy.

I have a funny story with Dr. Rios. I didn't work with him a whole lot. He and Peter kind of — Peter would take off and not tell Dr. Rios, and Dr. Rios had to handle Dr. Mansell's patients and his, so he took it out on us, yelled at us. I didn't know he was going to be gone; didn't tell me either. Anyway, Dr. Rios, one of his patients, he and his partner decided to have a little holy union before he died, so we went to his little apartment, and he was so sick he could barely stand up and make it into the living room, and they played the most beautiful — I wish I knew who sang it — the most beautiful rendition of "Somewhere Over the Rainbow." I mean, we were all in tears. Well, in just a little bit, the cat comes in the room and starts yacking. I think we all started laughing.

SCHWARTZENBURG: Killed the mood.

WARE: Yeah, it killed the mood. Cat yacking, that was so funny. It was like yeah, that's kind of how the world works, you know, the best laid plans.

SCHWARTZENBURG: That's right. Do you have a plan? God laughs.

WARE: Or the John Lennon, life is what happens while we're busy making other plans.

I think that's in one of his songs.

I know another story about Dr. Mansell that was very poignant to me. When the patients were so sick and dying with the Cryptosporidium, someone told him that cattle would get it, so Dr. Mansell called the Texas Cattlemen's Association and said, "Can you tell me how you treat the cattle? Maybe there's some way I can reduce a dose or use the same medication and help my patients."

And the guy got real quiet on the phone. He said, "Dr. Mansell, we shoot

the cattle.”

I mean, there’s no cure. There is no cure for it. You hear on TV, you know, if you have runoff in ditches and into waterways, people get it, and man, it makes you sick. But of course, they had no immune system, and it was just deadly for them.

I mean, he said, “Sorry about that.”

Dr. Mansell told me that, and I swear my heart stopped. It just stopped. It was like, “Wowser.”

We’d have to tell them not to eat organic food because it may have fertilizer, cow or cattle — using organic fertilizer, and to stay away from it because they could get things from it that could really be deadly. They got the bird TB [tuberculosis], that avian — what is it? I can’t think.

SCHWARTZENBURG: Flu?

WARE: No. A lot of times, they would diagnose it as TB, but it was a bird-type, avian mycobacteriosis. I think that’s what my brother had. Just the strangest things not seen in humans.

SCHWARTZENBURG: Just because they’re so susceptible to everything.

WARE: Yeah, just anything and everything.

Another thing about my brother, and this was in 1988, and I always tell everybody that I would put condoms in his Christmas stocking and my children’s Christmas stockings, I was always putting condoms and trying to talk about safe sex, blah, blah. So I got a call from Larry, Vickie and I were — southwest part of town, neither here nor there. He said, “Hey, I was with a guy last night. He had AIDS, but he said it’s in remission.” That was another time my heart stopped.

I said, “Larry, AIDS doesn’t go in remission, hon. What were you thinking?”

About six weeks later, he had that prodromal kind of flu-like — I mean, it was classic, just classic. Took him to the Montrose Clinic and had the HIV test, and sure enough — and he was positive. So he lived four years, and that’s because my mother took care of him. I’ve always said she literally loved him to death. If it weren’t for her taking care of him, no way he would have lasted that long. That’s like God, you know, you teach them, you teach them, and you buy them books, you buy them books. It’s like man, I hope it was a good one.

SCHWARTZENBURG: Just to wrap up, when you think about that time and your role in it, what are your thoughts?

WARE: I’m very proud. It was an honor. It was such an honor to be with them during their life, during their death, at their death. Like I said earlier, it was the best of times and it was the worst of times because I met such neat, neat men, because all of them were men, and their families. I wouldn’t trade it for the world.

Would I do it again? Not at this age, I don’t think, but yeah, I’d do it in a heartbeat, because that’s what I dream about, the patients, when I dream



Chella Ware, 2018.

about them, that they’re healthy and they’re coming back to see me when they’re healthy. SCHWARTZENBURG: Of course, you never got to experience them

healthy.

WARE: No, not very much. Sometimes they would come in right at the beginning of their diagnosis, and then you'd just see them, this beautiful, beautiful man, just lose 100 pounds, just look like a skeleton. That was one of the things that was really hard on them. I mean, we're all vain. My brother didn't go to my daughter's wedding because he looked so bad. People didn't even know who he was. He went to the rehearsal dinner, and there were people that didn't recognize him, and he did look bad. It was probably a couple of months before he died, and he was just ashamed and vain. He didn't look good at all. That made me sad.

SCHWARTZENBURG: Well, I'm proud of what you did, also.

WARE: Thanks. I think my kids are, too, because Kelli was telling somebody — we were eating with some people. She said, "Mom was one of the first nurses to work with patients with AIDS." I didn't even know she even realized that. I am very proud, and like I said, I'm very honored. I think the two times it's just the most honorable to be with people is when they're born and when they die, especially when they are by themselves. I didn't want any of them to die by themselves. That's my story.

SCHWARTZENBURG: Thank you for sharing.

WARE: Thank you. Thanks for letting me.

[END OF AUDIO PART 2]

[INTERVIEW CONCLUDED]

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