“HIV in My Day” – Interview 59

February 5, 2019
Interviewee: anonymous (P); Interviewer: Jackie Haywood (JH)
Interview anonymized at participant’s request

Jackie Haywood: Hello, [name]. Thanks for coming in from [city] on a cold day. So, tell me about yourself and Vancouver. Were you born here, did you come here from another area?

Participant: No, I was born here, born in Vancouver.

JH: And you mainly lived in the city?

P: Mhm.

JH: What were neighbourhood were you raised in?

P: [Intersection]

JH: What’s that called? Is that [neighbourhood]? Just trying to think of the name of that neighbourhood.

P: I don’t know what you call that area, we just called it the West Side, but it’s not, it’s just kind of…

JH: So, when did you first hear about HIV, or was it called HIV when you heard about it?

P: Well, I guess around ’86, ’87 when it was big news.

JH: What was the news that you heard?

P: Just that these people were dying of this disease that they didn’t know what it was.

JH: Was it mainly in newspapers or television? What was the source of information?

P: Gees, that’s a good question. I just heard it on the news. I don’t know.

JH: Did you and your friends talk about it in your circle?

P: Not really, because it apparently was a gay disease. Yeah, so I guess – I don’t know, ’85-ish I guess.

JH: Was the news that you and your friends were getting, was it blaming gays or…?

P: No, they were just, I guess, scratching their heads wondering what this disease was.

JH: When did you meet your first HIV positive person that you were aware of that they were positive?

P: Myself.

JH: Can you tell me more about that?

P: Okay, so I was going out with this guy at the time in 1987 and it was just like big news, so he just suggested that – I don't know if he suggested if both of us get tested or just myself – I can't remember. But of course, I went to get tested and it came back positive, and I didn't believe it, and I went back several times to get tested because I didn't believe my diagnosis.

JH: Where were you tested – community testing or with your doctor?

P: Um, theinfectious disease clinic at VGH.

JH: You went right there to get tested?

P: Mhm.

JH: And did they welcome you to get a test or was it… because we probably didn't think about women becoming positive then.

P: They didn't question, they just did it.

JH: So, what was then the next step for you then?

P: Complete denial.

JH: What kind of form did that take for you?

P: Well, I guess I just basically shut down and decided that I didn't have it and I was going to live a normal life. And the guy that asked me to go get tested, he broke up with me because he didn't understand the disease, and he… Yeah, he just kind of got out of my life.

JH: So, did you share this news with anyone close to you?

P: Nobody. I was in denial for nine years.

JH: So, what was that time like that? You must have gone to doctor's appointments, or no?

P: No, not at all. I was very healthy before I got the diagnosis, I was very healthy and active, and not taking any type of medication or vitamins or anything, and I was twenty-three years old.

JH: Did you notice your body starting to change or any…

P: Nothing.

JH: Did you date in those nine years?

P: Um… [Laughs] Gees, I can't really remember. Um, yes, I did. I think I was dating someone around '89 – well, I dated two guys after that and they were fine with it. Yeah.

JH: So, if you were in denial yourself, but you disclosed to people you were dating, what was that like?

P: Uh, well, I just kind of blurted it out. I can't really remember.

JH: But you made a choice to tell them.

P: Oh, absolutely yes.

JH: And they stuck with you in the relationship?

P: Yeah, they did.

JH: Did your physician know?

P: Eventually, yes, because I asked him to do another blood test for me as well, and then that was like in '95, basically when Oak Tree Clinic opened, so he referred me to Oak Tree Clinic after my diagnosis. [Laughs]

JH: Was that the first agency or organization particularly for HIV positive people that you encountered?

P: Yes.

JH: Can you tell us a little about those early days at Oak Tree?

P: Okay, so when I finally went to see them it was around '95, the end of '95, and I was starting to get sick. So, basically I told myself when I was diagnosed that I was just going to die gracefully and not go on meds, and that was going to be the end of it… [long pause] So, when I started getting sick, I went to see Dr. Burge at Oak Tree Clinic, and him and Glenda were both trying to convince me to start meds, and I was a little bit reluctant. However, as I got sicker, I just remember one night, just laying in bed, and I was actually seeing somebody – actually, that was the third person I was seeing after. And I hadn't disclosed to him yet, but anyways. I was – like, I had Greiger's, so I was shaking uncontrollably, no matter how many piles of blankets I had on myself, I just couldn't stop shaking. And then I decided I couldn't die like this, so that's when I started taking medication, so they put me on Bactrim for PCP prophylaxis, but by that time, my immune system was so low that I pretty much couldn't tolerate the Septra that they gave me. Yeah, so I had a reaction to the Bactrim at the time, so like kind of projectile vomiting, that's the main thing that I remember.

JH: Back to Oak Tree, alright, so now you're getting some medication, although it's disagreeing with you. You decided to stick with medication, their guidance, or did you step aside from it?

P: Well, I think at that time, like I was just so sick that I ended up with PCP, so I was admitted to the hospital for a couple weeks, and they did a bunch – they gave me a bunch of antibiotics, however, I don't know why they didn't come to the conclusion that I had HIV or AIDS. So anyways, they ended up putting me on pentamidine for the PCP, and I think I started taking the meds when I got discharged from what I remember.

JH: So, you were at St. Paul's or VGH?

P: I was at VGH because I worked at St. Paul's and I didn't want anyone to know, of course. So, I got admitted to VGH, and even at that time I didn't tell my family, because we were not a very communicative family and it was not nurturing. So, they didn't really ask me exactly why I was in the hospital, but they just thought I had pneumonia.

JH: And you did.

P: Yeah.

JH: Who were your support people then?

P: Pretty much didn't have anybody. Like I said, I just lived in denial, like it wasn't really happening.

JH: Were you living at home with your family?

P: At that time, I don't believe I was living at home, no.

JH: So, how were you treated at the hospital? What was it like in the '90s there, having AIDS or HIV and being a female?

P: I didn't notice any stigma per se, I just was oblivious, 'cause I was dying.

JH: In your mind or were you told that?

P: No, no one ever, thankfully, ever has told me I was going to die in "x" time.

JH: But that was your perspective on where this was going?

P: Oh, absolutely, yeah.

JH: Did you make plans to pass away?

P: No.

JH: You were just… So, did you get well and on your feet then after the pneumonia, a bit better or…?

P: Yes, I got better. What do I have to say about that? Okay, I got better, I got discharged, I started taking AZT and 3TC at that time, I believe, and I was also doing aerosolyzed pentamidine at home, for how long, I don't remember. Yeah, basically I just was trying to survive, so…

JH: Were you going into work? Were you able to work?

P: Not right after I was hospitalized, no.

JH: You were on sick leave?

P: Yeah. When I was in the hospital though, AIDS Vancouver, PLS [Positive Living Society] – I think they were combined at the time, I don't know – they did an outreach to my bedside in the hospital, and they gave me the information about PLS and AV, and I believe they also gave me information about PWN [Positive Women's Network]. So, I didn't access services right away because of self-stigma, fear – I don't know. I do remember when I did finally start going to PWN and one of the staff members brought me upstairs to AV to become a member – actually, I don't remember if it was AV or PL, 'cause I wasn't…

JH: This was in the building on Seymour?

P: Yeah.

JH: Upstairs was Positive Living, which was PWA at the time, and downstairs was the Positive Women's Network and AIDS Vancouver, so they took you upstairs to Positive Living.

P: To become a member, right? So, when I walked up there, there was only men and I felt like they were looking at me like what are you doing here, sort of thing. And I believe that they were all gay men.

JH: And Positive Women's Network was downstairs in that building. So, you became a member, anyway, at Positive Living, upstairs. So, you met your first group of – how was that for you, to meet positive women?

P: Well, there wasn't any positive women there at the time, it was just this staff member.

JH: But they had a presence, Positive Women's Network had a presence, but you hadn't met any positive women – is that right?

P: No.

JH: So, when you met a positive woman, what was that like – the circumstances and…?

P: I actually don't remember who the first positive woman was who I met, but obviously it was someone from PWN. I don't remember.

JH: How did that feel? What was that like for you knowing there were other females right here?

P: Well, obviously I didn't feel alone anymore, but at the same time it wasn't like we just sat there and compared notes or anything.

JH: And you stuck with Positive Women's Network – you returned and kept coming back or…?

P: No, I wouldn't say I got connected to services per se, no.

JH: I'm trying to paint a picture of what that was like for you or another positive woman, going into that environment.

P: Well, I feel like because of the type of person I am that I didn't also go seeking support as well.

JH: What do you mean by that?

P: Just like a very sheltered introvert.

JH: So, what happened next?

P: What happened next? So, I got put on a bunch of cocktails and I had different side effects. Yeah, it felt like the first few years on medication was – I just felt like a guinea pig.

JH: Because you were female or because of the time?

P: All of the above, because there were no studies done on meds, obviously, because they were new, and all the studies they did were on men anyways, so I was taking a dose that was for a 100kg man or 80kg man. So, I guess I was over-medicated.

JH: About what year was this approximately?

P: Well, I started in '96 with AZT, 3TC, and then, you know, they kept coming out with new drugs, so the cocktail was supposed to be better and duh, duh-duh, duh-duh. And my doctor kept telling me to hang in there and I felt like I didn't have any choice, so I would just suffer through the side effects of all these toxic medications.

JH: Did you talk to people at Oak Tree? Was there any kind of guidance there for you?

P: I wouldn't say guidance, per se. I would tell them my side effects and they would jot them down, and "Hang in there."

JH: Positive Women's Network, were they helpful to you or when did they start being helpful to you, or were they ever helpful to you?

P: Um, I guess they weren't really helpful to me because I didn't have the questions to ask. Like, I didn't ask questions, right? Like, I basically just thought this was an unknown disease, they don't know what's happening, I'm gonna die eventually.

JH: So, your social life, you continued having a social life? Did it effect your relationships or your dating?

P: Yes. Let me think about this. Okay so, I think I was with the last guy until about 2000, 2001. He wasn't really that supportive around the HIV, it was just not spoken about, it wasn't talked about. Yeah, like I said, I just lived my life as though I was normal.

JH: It sounds like you had a lot on your shoulders by yourself.

P: Yeah.

JH: At what point did you reach out to your family?

P: Did I what?

JH: At what point did you reach out to your family?

P: Did I reach out to my family?

JH: Or did you share…?

P: Well, another time, I was – I got hospitalized for something else. Yeah, and so I finally told my brother and sister, so they came over to my place – it was my brother, my sister, my sister-in-law, and my niece, I believe – and I finally just disclosed to them. And they had nothing to say 'cause I guess they were in shock, they didn't know – you know? Like I said, my family was not very communicative, so… I don't know. It was met with silence or shock or disbelief – I don't know.

JH: Did they have questions for you?

P: Not really.

JH: So, how about your job, or did you volunteer in the community? Any of your other relationships, how was HIV affecting them or not?

P: Okay so, I did a graduated return to work and I just worked like two days a week, I think. And yeah, no one ever came up to me and asked me about HIV or anything.

JH: What was your occupation?

P: I was a [job].

JH: So, you were right there.

P: At St. Paul's hospital.

JH: So, you came into contact with other HIV positive people as your patients or as your clients, did you not, or were you more behind the scenes?

P: Behind the scenes. No, we didn't see patients.

JH: So, when did you start being involved in the community, in the, let's say, women's HIV community?

P: Well, I attended some support groups when they had them, and yeah, I think that was around 2000 when I got lipodystrophy and I met a woman who had the exact same condition and became very good friends. I would say she was my first HIV positive real friend.

JH: So, how long was that from the time you were diagnosed before you met this supportive person, a friend.

P: Thirteen – no wait… Yeah, thirteen or fourteen years. [Laughs]

JH: That's a long time to wait, a long time to be in your own head.

P: Mhm. But I mean, that's just my upbringing.

JH: Do you still see her? Is she still…?

P: Yup.

JH: So, you met a friend and you were going to support groups. Is your community expanding now?

P: I guess a little bit. Like, I used to go – I've been to PWN in the past, for you know, the lunches and stuff, but actually that wasn't even in the old building, it was down here on Davie, so I didn't really do much when PWN was in the same building, because like I said, I lived in [city], so it was kind of out of my way and not convenient.

JH: So, you mentioned that building at the time, for you, it was mainly gay men. Did it make a difference when PWN moved out of that building into their space on Davie St.

P: I feel like it did make a difference, because the space was more welcoming but also they seemed to have a bit, I don't know, more programming. Yeah.

JH: They had more room, for sure. Did things change with your family that you mentioned as time went on and you became more grounded and had more supports? Did it change in the relationship with your family?

P: No.

JH: Did you become involved as a leader or a volunteer with the HIV community?

P: Uh, not in the beginning because I seriously, my brain just – I guess the trauma of the diagnosis just shut me down, and like I said, I was just waiting to die. And of course, as you see, I never did. Yeah, I feel like I've just been living with that trauma, I'm just kind of stuck even though it's been thirty-five years.

JH: Do you seek any other avenues to become unstuck? Is there anything?

P: I have tried, yes, definitely. I worked on the CHIWOS study.

JH: Could you say what that is, the CHIWOS study?

P: The Canadian HIV Women's Sexual and Reproductive Health Cohort Study. So, I got involved in that in 2012. Before that, I was invited to take the community capacity-building at SFU and I believe that was also through PWN. Yeah, and then it just kind of started growing from there because now I felt like I was part of the community and not outside of the community.

JH: And you're active in it and you were doing good work, like the research study, and you're doing work on yourself it sounds like. The community capacity building – how was that helpful?

P: Um, how was it helpful? I guess just to be more engaged with the community, yeah, the HIV community.

JH: Were you dating now – you're still dating as you were…?

P: No, I basically stopped dating. Oh, okay so, I guess the last time I was in a relationship was around 2009, '10, yeah. I would say 2008 – I'll just say 2008.

JH: So, views about HIV and people with HIV had changed a bit around those times, so was it easier to date men at that time?

P: No, it's not easier to date men and it's also not easy today, because I feel like there's no place to meet – oh, okay, I'm just talking about HIV positive men right now.

JH: Oh, okay.

P: But now because of the "U=U," I feel more comfortable in the dating world, I guess.

JH: Could you tell me about “U=U”?

P: So, undetectable equals untransmittable, so because of the new science behind that, I feel like it is easier to meet somebody who’s not positive if they are willing to accept and understand the science.

JH: Is it easier for you or easier for them?

P: I feel like it’s at least one less hurdle to get over, however, there’s still stigma out there, so it just depends on the person.

JH: So, would you say – what would you say could be any drastic life changes that you made because of your HIV status? I think I’ve heard a few of them, because you were on this track that I’m not going to live, so did you make any drastic life changes, decisions then?

P: Uh… Well, like I said, I just feel like I’ve been stuck. I’ve been ruminating a lot about my life and… Yeah, I just feel like I don’t even know where to start. It was just – I don’t know.

JH: So, where do you think you’re going?

P: Where am I going? I’m trying to go a lot of places, but I’m stuck. I feel like I’ve always lived with low-grade depression, so obviously that diagnosis didn’t help, and I feel like… I’m getting lost in my thoughts.

JH: That’s okay. I do that too. So, the difference between dating HIV positive men and non-HIV positive men, was that easier for you? How was the difference for you?

P: Well, in the beginning, okay so, I pretty much had my own self-stigma and I wasn’t going to date anyone positive, but then I realized that it would be easier to date someone positive. And then it’s like, well now where do I find them, right? Because there’s not really anywhere you can – there’s not a pool of positive straight men that you can just, you know, go to and say, yes, I want to pick this one or this one.

JH: I’ve heard that before. What about online or through magazines?

P: I’ve never tried through magazines, I’ve tried online. There is a positive site but they are very few and far between – I mean choices, yeah, and seldom in the same area.

JH: The population of HIV positive heterosexual men is small.

P: Very small.

JH: So, what are you involved with now as far as agencies go, and studies.

P: I’m still with CHIWOS, however, we’re not doing the surveys anymore, we’re doing more into analyses and abstracts using the data we collected. I’m involved with an organic co-op as you know, so that's still going, and that was born out of the community capacity-building course, I mean, not my own project but my colleague's project that I'm still floating.

JH: So, tell me just a little bit for the history about what you are doing with that organic co-op.

P: So, initially it was just for HIV poz people and then we expanded it to basically anyone living with a chronic illness. And it's pretty much open to anybody now, because we want the capacity, and I feel like it's an important program because food is more expensive these days. And of course, eating organic is better than not.

JH: That's hard work. I've seen your co-op at work and it's hard work. Are you up for that?

P: Well, it gives me a purpose, for sure. Yeah, I feel like after my diagnosis – well, not after my diagnosis, after my PCP, I felt like I lost my purpose in life, because it really kind of put a guillotine on my life. And I just haven't been able to figure out how to get back out of it.

JH: Sounds like you're doing some things.

P: Some things but I know there's a lot of other things I need to do to be more successful in my life.

JH: Some people say HIV was predominate in some positive things in my life, or this happened or that happened, or I was able to do this. Do you have any of those thoughts?

P: I do have those thoughts. I feel like I probably would be dead or in worse shape if I wasn't diagnosed, 'cause of the lifestyle I was living. I have met some good friends because we're all positive, yeah, so that has been a gift.

JH: There's a women's group out of Positive Living or Positive Living supports in some ways. Are you part of that group?

P: If you're talking about the SWING group, no. I don't know what group you're talking about.

JH: I can't remember what they've called it. I can't remember what they've called it – VIVA, that's it. It just came to me.

P: Okay, VIVA is an online group – it's strictly online. Have I been a part of it? I'm on their mailing list so I see the postings on it, however, I wouldn't say I'm an active member. So, I believe Oak Tree Clinic, they got funding to start some support groups way back – like, for quite a few years they've been going, and now because of the funding cuts, I think we lost one group that was Downtown Eastside, so I'm a co-facilitator for the one at Oak Tree. And they also have the SWING group at PL, so it's only for Indigenous. Oh, wait a minute, so there used to be actually four, then one got cancelled at Positive Haven in Surrey and now they cancelled the one in the Downtown Eastside, so the only ones that are left is the one at Oak Tree and the Indigenous group at PL.

JH: And what did you call it – the swim, swing…?

P: SWING. I don't know what it stands for.

JH: I just didn't hear it clearly and I wanted to capture it. So, the Oak Tree Clinic, the group that you co-facilitate is not going on any longer or…?

P: Yeah, it's still going, and it goes once a month, we have it once a month as with the other groups too.

JH: Do you socialize outside of the HIV community at all?

P: Um, not so much. Most of my friends are positive, actually.

JH: There's a definite community that seems like it was a long time coming for women. So, what advances have there been for women, through your eyes, and HIV over the years? Where can women be now with disease?

P: Well, there's a lot more programming for women, there's a lot more studies happening for women, I think. Yeah, it's great.

JH: So, what advice would you give to a newly diagnosed woman, a young yourself diagnosed woman?

P: Well, you can pretty much lead a normal life – well, it's a manageable disease now versus you have a death sentence, which I don't believe people are saying that anymore.

JH: That's a relief. So, what about the medical community? What advice do you have for them in looking back and how you're treated now or your treatments now?

P: Well, obviously listen to your patients with empathy. Yeah, things have changed a lot since I was diagnosed, so I feel like – yeah, there just seems to be more awareness about how practitioners should be treating their patients or vice versa, the relationship between the two. Like, it seems more equal versus, you know, the doctor up here and the patient down there.

JH: Right. Have you done any activism, been involved in any activism at all or advocacy?

P: Um, no, I wouldn't say – yeah, I'm not that type of person.

JH: So, if you could create an organization for women, HIV positive women, what kinds of things would you want to be a part of that organization? How would that look?

P: Oh, that's the kind of thing that we've been asking with our survey. So, how would it look, a women's organization? Well, I feel like a community kitchen, definitely, 'cause women are all about food and sitting around the kitchen table, and you know, preparing food or talking, whatever. Definitely some advocacy, you know, with legal issues, housing, social issues, like everybody else needs – counselling, of course that's very important. Even complimentary therapy like massage, acupuncture… yeah.

JH: It sounds like you're describing Positive Women's Network.

P: Yeah, which we lost, right?

JH: That is a loss.

P: And some, you know, continuing education programs, like that just helps to empower people.

JH: Oh yes, that's important. So, is there anything that you and I talked about that you'd like to expand on before we kind of wind down? It's a great opportunity – you've just been really helpful, so is there anything…?

P: I just feel like a lot of my experiences are from the older days.

JH: That's what we want.

P: There's just so – like, the environment is just so different today.

JH: Part of this study is to capture the history, the oral history of HIV/AIDS in Vancouver and compare it.

P: Yeah, because I can't say – like, I wasn't a very active member in the community back in the day, so just basically started being more part of the community in the last ten years, I would say.

JH: Are you enjoying your involvement?

P: I am enjoying my involvement, I would just like to do more with my life, and I feel a little bit stuck.

JH: Anything you'd like to add? Anything you'd like to expand on?

P: Um, just happy that there are so many studies going on for women and HIV. Yeah.

JH: Good. Okay. Nothing else? This is it.

P: Not off the top of my head. I can't think of…

JH: Okay, well thank you.

[second interview clip]

P: Yeah so, so I had a few significant side effects that I would like to share. So, I was on one cocktail – okay, as you see, I have Asian hair, and I swear it was so toxic that my hair curled like an African – like, tight, tight curls. So, that was one side effect, and then like the peach fuzz on the face.

JH: Do you remember what drug that was?

P: Well, I know – yes, I'd say it was indinavir, ritonavir – yeah, the DDI, so that was the combo I was on, which also caused my lipodystrophy. So, that was one, so kind of losing hair but gaining peach fuzz on the face, and like I said, very tight curls in my hair. Another side effect I had was on tenofovir, which dried out my salivary glands and I couldn't masticate, so I ended up getting a feeding tube because of it, so I was on that for I would say a couple of years, something like that. Um, I think those were the major ones that I can think of.

JH: Because your hair is very straight. I can't imagine it curly.

P: Yeah, so I think the one that hurts that most is the lipodystrophy because I've lost all the fat on my body and I just feel like I'm not a full person because I can't fit into clothes that are made for normal people, and I'm already small as it is, so you know? I just felt like all my life I've had troubles just even fitting in – like, the sizes I wear are always in between because of I guess our society, how we look at the physical. Okay actually, to tell you honestly, I've lost so much fat on my butt that my anus shows, like I don't even have flesh to cover my anus. So, that's the one that I think hurts the most right now. And that's it.