“HIV in My Day” – Victoria Interview 10

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Interviewee: Anonymous (P); Interviewers: Art Holbrook, Charlene Anderson

Art Holbrook: Okay, we’re in action. So, now that we’re old friends, would you introduce yourself? We’ve been here for so long, please introduce yourself.

Participant: My name’s [name] and I’m from Northwest Territories. I moved here about twenty years ago and stayed there for about twenty years, and then Vancouver for about twelve, twelve years.

AH: Okay. Would you take your cap off? We got a lot [inaudible] coming down there.

P: Oh yeah, sorry.

AH: Good, thank you. So, you’ve lived here for twenty and then over there for twelve, or in the middle was it the twelve in Vancouver?

P: I’m sorry?

AH: You lived here for twenty and then over there for twelve?

P: Yeah, I’ve lived here for about twenty years.

AH: Yeah, yeah, okay. So, how’s the community changed over those years?

P: I’m sorry?

AH: How has the community changed over those years?

P: Well it’s changed quite a bit there. I mean, I hang around downtown, like down around Our Place and there’s quite a changeover. There’s new faces, but there’s still a few of the older ones, but the majority of them are new. And so, it’s kind of sort of like a catch two-two, you know, like because of the fact that they cater to the people that use injection, and for them to do that is kind of, I don’t know, it goes against the grain I guess. But still, you could see from their point of view to prevent the ODs and HIV and Hep-C and things like that, especially these days because a lot of the people aren’t street smart or educated enough to really say well, I wanna try this, I wanna try that. And it’s sort of like a toss up, but especially these days because of the fact that they have fentanyl. Fentanyl has changed a lot of things, it’s changed a lot of lives.

AH: Well, you’ve answered the last question.

P: I’m sorry?

AH: I say you've answered the last question on the list, so we're ready to go now. Let me go back to the beginning. So, when did you first hear about HIV/AIDS?

P: Uh, in 19… In 1992. It wasn't really, it wasn't really that well known back then, and nowadays it's very well known. There's more awareness of it. And for me to go—to have it now, compared to back then, I think back then they didn't have no medications, like it was a new thing. And from what I've seen, it's kind of like playing roulette, taking a chance. With me, I took a chance and I became positive because of the fact that I used somebody else's needle. No smarts. Ha. And see like, but then I used to work in a needle exchange for eight years, and during that eight years, I figured there must've been close to a thousand cases of HIV. Like during the time I worked untPthe time I finished, about a thousand cases of HIV sprung up over the past eight years I was there.

AH: Was that in Vancouver or here?

P: Yeah, Vancouver. And here it's kind of new over here – well, it's not really new but it's not, there are not really that much services available. I mean they have the basics, I'm sure everybody had the basics. But still, Vancouver's more… more – how do you say, better equipped. Better equipped to handle it, they have more resources than here.

AH: Well, that's probably not too surprising being a much bigger centre.

P: I'm sorry?

AH: I said it's probably not too surprising being a much bigger centre, but still. So how did you first learn about it—about AIDS?

P: How did I first learn about it?

AH: Yeah.

P: Well I used to go to an HIV support group before I became positive. Like a friend of mine trusted me to go to his group, he invited me to his group, he was, how do you say—chairman? Chairman, I guess—moderator. Yeah. And he took me under his wing and showed me a few things and a couple of years later, 2001, I became positive. And that changed my way of thinking. I'm sure it changed quite a few people's way of thinking, for the fact that it was very rampant back then. I mean people didn't, they didn't know what they were dealing with. I mean they're—a lot of people shared rigs, had unprotected sex, used water from a toilet of all things. I've seen somebody use water from a toilet. Nah, that's hardcore. It is. It is. Like when they opened that needle exchange, I was the one who kept it open after hours, like they used to open from six o'clock in the morning 'till nine o'clock at night. After nine o'clock at night, there was nobody there to hand out needles or nothing. So, I just took it upon myself to go in there, open the office and give out needles. And then I got shit for that because of the fact that I wasn't supposed to be in the office after hours. But I explained to them the rationale for—I said after nine or after eleven at night, people are looking for needles. It doesn't matter what, yeah, people are always looking for needles. I'd rather give a whole box away than see somebody else share a needle. The rationale behind it back then was, well, they're only—from six in the morning from nine 'till night. So, I more or less kept it open right 'till two or three in the morning, sometimes even four, and then I'd close the door. So, I was more or less just like an outlaw.

AH: So, when you became positive, how did you respond? Did your behaviour change, did you learn about the disease?

P: Yeah, my behaviour changed. I mean, at first, I denied it. I mean, everybody does. I denied it and I didn't take no pills or nothing for two years. And I finally went to see Native Health in Vancouver and there was this one doctor there, Dr. Adleman. He was the one who started me on this Truvada, Truvada and then a pink pill and a Truvada. A pink and a blue pill. And within three weeks of taking it, my viral load shot down over 134,000. I mean it was way up there, but it shot down 134,000 in a three-week period. So, for me to stop taking them, it would probably, that was probably the last thing they can give me, more or less. And I stuck with it ever since. I still take it every day, whether I need to or not.

AH: So, you avoided AZT?

P: I'm sorry?

AH: You didn't take AZT?

P: No, I never took anything for the first two years of my diagnosis. And I used to wake up in the morning with heaves, dry heaves. And I was wondering how come I get them dry heaves and finally I went and got a blood test and they told me I was positive. And my first reaction was anger, and denial. You know, nope, nope. I got right mad, you know. The street nurse that told me about it sort of looked at me and just backed off. And I more or less told her, it has nothing to do with you, just the fact that you told me. That just blew my mind away, blew my mind right away.

AH: So, you said your behaviour changed. What sort of things changed?

P: Well, for number one I used to go out and work, work for money to get—to get my happiness, I guess. But it wasn't happy then. And then I quit, I quit doing coke and ever since then, I found out I have a life. You know, this is the best I can do with it for now, and for me to throw it away, it's just not made to do that. I would advocate for somebody who had, or anybody who has HIV. I would speak on their behalf. Like, a few times I brought clients over to AVI, and they said, "You can't do that," they told me. Well, I tell them, "Well, he's HIV positive. They have no other place to go." Because I used to bring clients right to their office, the old AVI over there. I used to get shit for bringing people there and I'd tell 'em, "Well, they're positive." They're "Do you know that for sure?' I said, "Well, he's not going to lie to me."

AH: Yeah, that seems kind of odd.

P: I don't think anybody would lie about being HIV positive.

AH: So, did your social life change any during that time?

P: Yeah, yeah, for the most part I used to just be on the computer and just shut everything off. But these days I'm out more, going out more. I go to a swim pool two or three times a week. I go out for walks, spend a lot of time with my granddaughter. I found out I have a reason to live. She's pretty cool.

AH: Yeah, granddaughters do that to you.

P: I've watched her grow up, when she was just a little—from day one to she'll be thirteen in May, of all things.

AH: One of mine just turned fourteen a week ago or so. Giving her parents a lot of trouble, but being a grandfather, you just get to relax and watch it from the sidelines. So, how did your identity shape your experience of the epidemic? I mean, you're a First Nations person. Did that influence how you experience the AIDS epidemic?

P: Well, I guess in a sense it did because of the fact that, well, you figure there's at least ninety-percent of the people in the Downtown Eastside are natives, and it's easy for me to blend in. Like I mean for – like they used to be people in Oppenheimer Park, used to ask me to show people around or to explain what they're doing there or what kind of services they have and everything, and most times I find that a lot of people are ignorant. Not through their choice, they just don't know.

AH: So, did HIV alter your feelings about your identity as a Native person?

P: Well, I'm still a Native, irregardless.

AH: Ah well, there you go. I need re-phrase that question, I think.

P: Yeah, I mean, it does have an impact on me, because I have to explain to my family what happened to me. And they live in a small close-knit town up in the Territories. Now, if I was to go back there, I would be left alone because everybody doesn't know what it is. I mean, they have some idea, but back then, they didn't know what HIV was and they're scared of it. And anything they don't know, they fear. I'd be given a suitcase and told "Get out." Yeah, back then they'd just tell me to "Get out. Don't come back get out."

AH: Down in Vancouver, did you, because you had the—I don't have the right name—the Native Resource Centre, place like that. Did you have the same or did you have more or fewer resources than say, the average white guy?

P: Well, back up in the Territories, I have I think maybe one, Yellowknife might have something, I'm not too sure of anything else. Like my – the place where I'm from, the doctor's only there once or twice a week. And for—I'm more or less lucky I think I stayed here, because of the fact that there's more resources and people are more understanding. Whereas back home I'd be given the cold shoulder and be off, they'd tell me.

AH: Ostracized, yeah. So, shift gears a little bit here, what was the medical response to the epidemic? You mentioned some resources that were available to you. What was the response like from the medical community?

P: Mine? Or?

AH: To you, from the medical community.

P: Oh, when I first got diagnosed, it was just like a different world opened up for me. People were more receptive, more understanding, and I found that I'm not alone. At first, I thought I was, but I'm not. I mean, there's how many thousands of us?

AH: So, are you saying that AIDS opened up a community to you?

P: Yeah, more or less so, it was an eye opener, I'll put it that way. Like, I'm more aware of my—my—more aware of my demise.

AH: Yeah, I'm getting along in years. I'm thinking about mine too.

Charlene Anderson: I have a question—[name], when you got diagnosed, did you go with the—get your treatment stuff from the Native Health Authority, or from St. Paul's? Like was there a difference at the time? Were they together, or was there a response from Native Health?

P: No, I think when I first started taking medication I went to Native Health, and like I said, a doctor prescribed me a pill, I had to take one pill a day—or two of them actually—and I've stuck with it ever since. And my viral load is next to none, and my CD4 count is over three hundred or over four hundred. Before there was about eighty, ninety, and then all a sudden it went right up.

AH: So, you had a pretty good response from the medical community. What about government? Any ideas about how government responded to the epidemic?

P: The government, oh wow. Well back in the early times, I think the government just shuffled them aside and just said, "There, that's you guys over there. We'll just leave you there." And nowadays, they're more open and more aware because of the fact that it doesn't just affect people that are poor, it affects everybody. It affects everybody due to the fact of the cost, the cost of the medication. I'm sure the taxpayers—or the government or whatever—used to shun people that are HIV, because of the fact that money, there's money to be handed out. But then again too, with HIV there's money to be made, I guess. Well, it's kind of like a catch two-two, but…

AH: So, in your experience, how did the public react to the epidemic? Did you face stigma or discrimination or any of those kind of things?

P: Yeah, yeah, I faced quite a few times where I was stigmatized. People would look at me out the corner of their eye and more less see if I'm going to infect them or whatever. They more or less look at me out the corner of their eye, and nowadays, I don't have to deal with that anymore, because of the fact that it's more open now. Before, it was all under the rug, it was all shuffled under the rug. And nowadays it's more open, treatment options are improved over a hundred percent, over a thousand percent, I figured.

AH: So, you experienced some discrimination in the past—

P: Yeah, I have.

AH: But that doesn't count nowadays?

P: I'm sorry?

AH: That's not the case today? You're pretty well accepted?

P: No, no, it's not anymore.

AH: Oh, that's interesting. Did the fact that you were stigmatized influence how you felt about yourself as a positive person?

P: For a while, it did, yeah. You know, I used to think, well, what's my worth? And today my worth is lots. Like, I write poetry, like I said I wrote a poem about a quilt, the quilt they have the—what the hell do you call that place again? Dr. Peter, Dr. Peter's Centre, same with that gong—that gong—I had to have a reading for that gong. Like, when they have their AIDS Walk, they have that big gong in Vancouver, where somebody reads something, and then they ring it, and then they read some more. I wrote quite a bit of poems about people that are HIV. Like, downtown HIV IDU consumer core, I've worked there for eight years. And a lot of times people—people are marginalized there. Very marginalized.

AH: In talking about the public and the fact that there was stigma and discrimination, did you also see compassion from people in the public?

P: Yes, I have. I've seen quite a few people that were, that welcome you with open arms. They don't look at your past, they accept you for who you are. That's probably the biggest change for me, I got accepted for who I am.

AH: Were there any groups that—as the public became more aware and responded, were there any groups that were excluded?

P: I'm sorry?

AH: As the public became more aware and compassionate, whatever word there, were there any groups that were excluded? Were the IDU people pushed aside by the public or did that—

P: No, I think it more or less became… blended, became blended together. I don't know how to explain it, but I guess what I'm trying to say is people are more aware, they're being educated, and being accepted is a big thing. You know, I mean, I'm HIV positive, I even wrote a few things on Facebook that said I'm HIV positive. If you wanna judge me, judge me so I can move along. You're gonna pass judgement on me, do so, I wanna move on. And then actually quite a—I figure about eighty percent of my friends responded and said, "We're not judging you, we accept you as you are." That's a big plus.

AH: Yeah, for sure.

P: Being open and honest about it is probably the best thing I ever did.

CA: It's much easier, eh?

P: Yeah, yeah. That's right, I don't have to look over my shoulder.

AH: You're not hiding a secret. You mentioned before that you've worked on some of the programs having to do with HIV, so how did you become involved in HIV activities?

P: How did I become involved? Was I used to go to a—like I said, I used to go to meeting before I became positive, this was about five years prior to that. And back then it was just a small group, there was probably about eight or nine of us, and now it's grown up to over a hundred.

AH: So, you've remained active in that group?

P: Yes, I have. I used to do a lot of data work, on a computer for different organizations [inadubile] HIV.

AH: Did you have any sort of social work or health-related experience prior to your becoming positive?

P: No, I haven't.

AH: So, were you involved in any aspects of activism about HIV?

P: Yes, I was. Like we used to promote harm reduction, and through harm reduction, it's a different ball game. It's not all bad, and it's not all good, it's sort of near the balance, a fine balance.

AH: But what did you do—you say you became involved with that, what sort of thing did you personally do?

P: I used to go to meeting like I said, and became sort of like an ambassador, an ambassador for the group.

AH: So, what were your ambassadorial duties?

P: I used to promote this group, I used to promote 'em, I used to write poems about 'em. I built a profile of each member, but they were anonymous, just their first name, build a profile. There was probably about—back then, there was about nine or ten of us—I'd build a profile for everybody to explain their strengths and weakness. I did a lot of research. Just like this, more or less.

AH: So, you mentioned that you posted something on Facebook. Is that recent?

P: I think last year was the last time.

AH: So, you're still a digital ambassador are you?

: I'm sorry?

AH: I said you're still a digital ambassador.

P: Well yeah, I think I'm even gonna post something again about it today.

AH: Well, tell them how nice we were.

P: Yes.

AH: Actually, do encourage people to come in. We're hoping to get more interviews than we've had. So, how did the positive community deal with the care and support of people as they declined, back in the days when the drugs weren't so effective?

P: Well, through – I guess through support, I guess, giving 'em more support and physical support, like taking them to the doctor. Take 'em to their doctors, be with them, I guess, just to show them they're not alone.

AH: So, you used to do that kind of thing—

P: That was before I became positive.

AH: --but you did that kind of thing back before you were positive?

P: Yeah.

AH: Right. So, you knew what you were in for when you became positive. So how has the—I'll go back a bit here—so how did people deal with the grief of so many people around them dying? So many friends, lovers, people they knew, dying?

P: Well, for myself, the way I dealt with it was I put in the back burner and then I let it sink in, and then I deal with it then. All the negative feelings that I more or less dealt with it, I don't let it bother me, although some of them were pretty cool friends. For them to be here one day and then gone the next, that's kind of harsh, but that's life I guess for—life in the fast lane, I guess.

AH: So, how did the AIDS epidemic change your community, either your native community or your IDU community? Maybe talk about both please.

P: With IDU, people were starting to change their behaviour, they didn't share rigs anymore. 'Cause they—I mean once a rig is used, it's used, it's dirty. You can soak it in perfex or whatever it is, it's not gonna clean it, it's still dirty. It doesn't matter what you use to sterilize it or whatever, it's still dirty. Infected the needle part, the needle tip.

AH: Ah, I didn't know that. News to me. So, what about the native community, how did that change?

P: What?

AH: The native community, did it make changes in the native community?

P: Well, for the natives, they've been through—they've probably had it worse than people who were not natives, because of the fact that they were shunned, they were put on the back burner and left there for a long time. They were treated as second class citizens. For me, the way I dealt with it was "I'm here, deal with me. If you can't then that's your problem, not mine." I more or less stuck up for myself, nobody else is gonna stick up for me. Number one, I put myself in that position, and I have to live with that. I'm living with it everyday. A lot of times I more or less say the hell with them, I'm just gonna go back to using again. But I don't. I just think, I think I probably owe a big thank you to my doctor, my Dr. Adleman. I haven't seen him for a while, I have a new doctor now, but back then he was—he said, "I'm not gonna bullshit you, you're on your last legs." I mean my viral count is way up and my CD4 count is way down. "This is your last chance," he says, and gave me these two pills. Like I said, my viral load dropped down over a 134,000 in three weeks. It was over eight-hundred-and-something, it dropped down in three weeks of taking these pills. And I've taken 'em ever since.

AH: Are you taking any of the new drugs that have come along?

P: Nope, just Truvada and a pink one, that was it. That's all I need. Like, before a specialist there tried to give me just one pill a day and it didn't work, my body reacted to it. I would literally fall right now. I mean I'm walking alone, I'd fall right down. The effect of it wasn't pleasant.

AH: Doesn't sound pleasant. So, looking back over the last – what is it? Getting close to twenty years since you became involved with this, how has your perspective on AIDS and the AIDS epidemic changed? How do you perceive it now versus then?

P: Well, these days they have—like I said, they have medications, they're developing new medications just about basically every day. And if people would stick to their meds, they have a chance. There is a chance for a cure. There is. I believe that. Just like a cancer, there's a cure for cancer too. There was even a report, a study done where somebody was given stem cells from someone in their family and became cured of HIV. I don't know if it's true or not, it was I think over in Europe. Somebody was given bone marrow or something, became negative. Like I don't know if it's true or not, but there was a story written about it.

AH: Were there a lot of rumours back then? I mean you talk about you don’t know whether that’s true or not—

P: I’m sorry?

AH: I say, you don’t know whether that story is true or not, but have there been a lot of rumours about the epidemic over the years?

P: No, I don’t think, I don’t think, not that much, because of the fact that it’s more or less it’s accepted as-is, I think. It’s not really an epidemic anymore, because of the fact that they can control it with medications.

AH: But back then, back in 1991 or so, were there a lot of rumours then?

P: I’m sorry?

AH: I say, back in 1991 or so, when you became involved, were there a lot of rumours then? You know, because people didn’t understand the disease?

P: Well, due to the fact that people live on dreams, I think anyway, at least I do. What I mean by that is they have a hope, they’re clinging onto a hope. And a long time ago, people would sort of linger in the shadows. And now they don’t have to. Because of the new pills these days.

AH: So, is there any advice that you would give to health care professionals?

P: Any advice?

AH: Yeah, at where we are now, with pretty good medications—not cures, but medications—is there anything you would say to health professionals now?

P: I would just say look beyond the surface. Look beyond the surface. There’s – there’s something in me, you know, there’s something in everybody, but I’m just saying that if you look beyond the surface, then you’ll see a change. For me to be—like I used to inject, inject coke. When I became positive, I changed completely. That changed my way of thinking, and nowadays I’m more or less thankful that I’ve quit. I’ve been given sort of like a new chance because of these meds.

AH: Anything you would say to the politicians these days?

P: I’m sorry?

AH: I said, is there anything you would say about this, about where we are today to politicians?

P: To the politicians. Everything goes in this ear and out the other. If there's no money there then it just goes right through. But I think politicians, they're involved in some ways, I'm sure they are, they're the ones that make decisions about our pills, about our meds, things like that.

AH: So, what about future generations? I'm hearing stories that people because these new medications are out there, people are more relaxed and not taking preventive steps, so that the rate is going up.

P: Oh wow, it's uh, I really don't know what to say. There's times when I used to think, well, what is my worth. If I don't—if I had just, you know, turned around and walked away, I don't think I'd be here. I'd of been down under, I'd of been six feet under. It's a change, it's a change, it's sort of like a new lease on life. That's the way I look at it anyway, I was given another chance.

AH: But let me ask a different way here. If you were to see someone from your community in Northwest Territories who had come down and was getting involved with drugs, what kind of advice would you give that person?

P: Well, I tried to see if they'd quit first, then if they don't, then I would direct them to place where they have clean needles, safe injection site, educated 'em I guess. By educating, I mean street smarts I guess is what it come down to, if you're buying from someone you know then that's the best route to go. I mean you can't go to somebody else and buy from somebody else because of the fact that they have this fentanyl nowadays, that's the big killer. Wow. I couldn't believe it, there was a guy given a fifteen-year sentence for dealing with fentanyl, that's pretty serious fifteen years. That's a big chunk of his life behind bars.

AH: Well, he might have been passing out death to people, so I don't think I feel too bad about fifteen years. Anyway, is there anything else that you would like to say, anything at all?

P: Well, just basically, I think medication takes, plays a big role in all of this. Medication. If they didn't have it, everybody would be gone. There would be no survivors. I mean, you only survive for so long without medication, but I'm just saying that a lot of them won't survive. Because medication, it's a new, like I said it's a new lease on life, it gives one hope anyway. Because I do believe there is a cure.

AH: Well, that's a pretty positive note to end on. Do you have anything that you wanted to add?

CA: What services do you use? Like what AIDS Service Organizations do you use in Victoria?

AH: In Victoria? AVI, just AVI. AVI and then I go to Our Place and I talk to an Elder once a week, and I even go to sweat lodge once a month. That's what I use anyway, and my pills.

CA: That's awesome. Thanks, [name].

AH: Thank you very much.