HIV in My Day – Interview 11

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Interviewee: Daphne Spencer (DS); Interviewer: Ben Klassen (BK)

Ben Klassen: Alright, just getting started this afternoon, talking to Daphne Spencer. Thank you so much for being here…

Daphne Spencer: You're welcome.

BK: …and for agreeing to share your stories about the epidemic. We like to start these interviews by asking people how they became involved in the gay community, whatever that looked like. So, how did you find yourself immersed in the gay community?

DS: One of my friends from college days was probably one of the first guys to get diagnosed with HIV in Vancouver and subsequently died of AIDS. So, at the time I was working at St. Paul's in ICU as a nurse. We'd been looking after the first few cases of HIV, but it was the death of my friend that sort of started me looking into – where I could maybe have some impact. And the direction I was going in was towards palliative care, because my friend had a partner who was able to look after him until he died, but at that time we were really realizing there were a lot of people who had no one – no close friends, no family to look after them. So, I was – in my first sort of vision, I was going to set up a palliative care-type centre, which led me down to San Francisco to look at what was happening at San Francisco General and to look at what kind of support services they were offering. And then when I came back, I hadn't figured out what I was going to do. Then along came Expo 86 and so I worked for them for the duration and during that time in my nursing magazine there was an article about Dr. Michael Rekart, who B.C. had recruited from California to come up and run the B.C. Centre for Disease Control. So, then I thought, "Ah, so maybe I should talk to him," and then the rest is history.

BK: So, you talked about thinking about palliative care and maybe setting up something like that. Was that going on in Vancouver at the time?

DS: There probably was palliative care. I didn't think or know if there was specific palliative care centers that would focus on gay men, because at that time most of the patients I had at St. Paul's were gay men. It was the dilemma that – many of the gay men I had talked with expressed that they were – they felt they were estranged from their families and if they didn't have – they may have come to Vancouver for care. They may not have been from Vancouver so they may not have known many people. So, for me it seemed there was a need for people who had partners who could maybe stay with the person during their palliative care, but also for people who didn't have anybody. So, that was the direction I thought I was going to go in. As it turned out, I went in quite a different direction and got into HIV testing. Who knows why. [laughs] Just coincidence.

BK: So, obviously I want to talk about your experience as an HIV testing nurse a lot and that's what we will spend the bulk of our time discussing, but since you were observing the epidemic developing in Vancouver – and before that too – and also had a little glimpse of what the epidemic looked like in San Francisco… Any thoughts on how the epidemic was manifesting in that context and how it manifested in those early years?

DS: I think Vancouver – the reason I went to San Francisco is it seemed that we were going to mirror what San Francisco was seeing and to me it seemed that it was the logical location. I mean, I could go to New York or Chicago – there was a lot happening there – but San Francisco was west coast, close by. I had contacts there, it was easy for me to sort of check in with health care providers and check in with what was happening with social services in the U.S. – different from Canada but it still gave me the idea. They were – it always seemed if we held a mirror up, what was happening in San Francisco, it would happen four or five years later in Vancouver. So, I thought, "Hm, there was a good place to start." They were extremely sophisticated for what they were offering in San Francisco. They had a centre in the general hospital that was very much like St Paul's. They were providing care that was nonjudgmental. They had some hospice situations, which interested me, but I – when I got back to Vancouver I realized it was a big step to start setting up a company – a hospice and – and my interest in sort of prevention sort of took over. So, then when I meant Mike Rekart, a couple of others at the BC Centre for Disease Control, I thought, "Hm, that's a good fit for me." It's funny, you start in one direction and you end up somewhere else, almost at the other end of the poll!

BK: It's interesting. How did that shift happen?

DS: Well, because, I think the reason I went the first direction was because my friend had somebody to look after him, and he had family who came to his bedside and showed up. And I was aware, keenly aware, that there were lots of men who didn't have that. So, that's why I went in that direction initially. But then I thought I could probably accomplish a lot on the prevention side of things and the education, so I did.

BK: Wow.

DS: Interesting.

BK: Yeah.

DS: Yeah, completely opposite.

BK: I wonder, was part of it just seeing how much further San Francisco was on those lines in terms of prevention, education?

DS: No, I think an opportunity came along. There was no one offering – no one other than physicians at the time offering HIV testing. It just seemed like it might fit my personality. So, I had a young family and it probably was easier for me to take a position that was already established than to invent something new. And I think Vancouver had hospice and had palliative care at that time but I – I think it was adequately looked after, you know, so I didn't think that that was – that I could easily have… For me, it was an easy shift for me to say, "Okay, I will go onto the prevention side of things." So, it wasn't anything I lost sleep over – I wasn't disappointed that I didn't do the other, but I do remember that was the direction I thought I was going to go in.

BK: And I suppose there were other organizations that were kind of starting to take up the burden of support for instance?

DS: I think May's Place was one of the original sites. I remember for a while one of the nursing homes out in Kerrisdale. Shaughnessy had a designated three or four beds. It was before the Dr. Peter Centre opened. So, I think there probably – the slack was picked up for care, I hope. But we still would hear stories of people passing away alone or in apartments in the West End. So, we probably were a bit slow. Response – it's hard to have responsive health care systems who have to move that quickly and – you may have heard from others. Fortunately, because of activism in the gay community things started to move quite quickly but not quickly enough for some. [pause]

BK: Since you have an inside view on this, what did the early medical – I mean you probably were not involved with this in the very early years of the epidemic, but do you have a sense of what the early medical response looked like in Vancouver?

DS: Well, I do because I was working in ICU and we were admitting people probably with PCP mostly and we weren't sure how much gowning we needed to do. I mean, we had protocols at St Paul's but they were evolving as the science was evolving, and they were – there was still a lot of fear of families, of care providers, worrying that – not being completely convinced that the science knew how HIV was transmitted. But that wasn't an issue for me, it wasn't an issue for my family. I understood the transmission. It was scientific enough that I understood it. My family weren't worried but – yeah. Now I think that – I love seeing how Vancouver has progressed, has embraced the new treatments as they have come along. I don't feel there were many obstacles to that care – I think we have kept up, if that's what you're asking.

BK: No, I think that captures it. I feel like the consensus of a lot of people is that Vancouver has been on or near the leading edge at least for developments such as these. When did HIV testing actually became available?

DS: Well, I was hired on at the end of Expo in '86. There was one nurse who had worked for several months at BCCDC before she took a position in Saudi Arabia, so I stepped in when she left. I think some physicians were offering HIV testing earlier than 1986 but then Dr. Michael Rekart started at BCCDC in 1985, 1986, I think, and he felt strongly that we needed to offer HIV testing there as an alternative for people who may not have a doctor or may not wish to go to their physician. But saying that, we were lucky there were physicians in Vancouver that became aware of HIV very early, went down to the U.S. to find out what was happening, and were diagnosing cases very quickly. And so those physicians were offering HIV testing as well. So, our BCCDC is public health so that was a – it was set up as an alternative for people where they could get a test with a – I won't say it was anonymous because I would have seen their face, but they didn't need to provide any identification. So, it was as close to anonymous as we could get. We weren't using a health care number, but we had face recognition.

BK: This is kind of an obvious question, but why was that so important – the mostly anonymous testing? Was that something people in the community were really advocating for?

DS: Yes, because I don't think people felt safe disclosing their HIV status in those early years and so, it had to be that way. But what was interesting was that once people were diagnosed with HIV, they weren't able to be anonymous because all care that they needed to receive after that point was with a physician and that would have been covered by your medical. So, people could – I think the anonymity provided folks the opportunity to find out their HIV status, the opportunity to talk to somebody they didn't know, to talk about prevention. It gave them a chance if they were negative to figure out what they could do to stay negative, if that worked for them. If they were positive, it also gave them a chance to – a little bit of a buffer to figure out, well, what was the next step going to be. And I think where HIV was sitting in society as far as how people were responding to it and who was afraid of it, I think we needed that opportunity for people to test with being relatively anonymous. I mean, you wonder whether in hindsight it was the right decision – I mean, I don't have any reason to think it wasn't but you look back… You always have to look back and think, "Did we make the right decision?" I think so. I think so.

BK: And so you have alluded to a lot of different aspects of what your role looked like but can you take us inside of that role?

DS: Sure, you mean walk you through what would happen? We had an office in the BCCDC which was on Tenth Avenue near VGH. People could walk in and make an appointment or they could telephone and make an appointment they could make that appointment under any name that they wished. They were called – I would go into the waiting room and call their name. There would be no distinction why they were there and why anyone else was in the waiting room. It was the waiting room of a STD clinic so that – but everybody – no one would know why each person was there. The person's file was given a number and the person was given a copy of that number. For the purposes of conversation, a name was exchanged. I would introduce myself using my correct name but I didn't ever ask the person if I was addressing them with their correct name or not. Some people would say, "My name is Harry. I registered under the name Harry, but my real name is John." I would say, "Do you want me to put that in the chart or no?" And they would say yes or no. I would say, "Do you want me to address you as John or Harry." He would say John or Harry, whichever one it was, and we would talk about what – I would ask them, "Why did you come to the clinic today and how can I help you?"

Sometimes people just wanted to have information about HIV. There was information out but it was gradually getting fine-tuned. If you had access to scientific journals, you could know exactly what was happening with HIV, but if you were a citizen just reading the paper you could have misinformation about HIV, or real information about HIV, or you might have heard something from a friend. So, I would try to explore what kind of information the person had – try to give them my version of correct information. I – we would talk about how HIV transmits. If there were personal instances that they were worried about, I would invite them to tell me about them. If they felt comfortable we would talk about that. We would have the opportunity to talk about, "Could – can you think of any way that you could have made that less stressful for you – that situation?" And we would – I was open to talk about those kind of things. Some people would decide to have an HIV test and some people would say, "Hey, thanks very much. I will think about it." And I think that is important because at that time there wasn't a treatment. There – it was a probable terminal illness.

And once people knew the way HIV transmitted, they could fit their personal situation into how it transmitted. If they had unprotected sex and if they had shared rigs, the chances that they could get infected were higher. And some people weren't ready to get tested, and I think of a lot of – so, my sense was there were folks who might have put testing off for a period of time - might have, just because they may have thought, "Well, there is nothing I can do for treatment, but the same thing I can do to prevent passing this along is the same thing I can do to prevent getting infected." So, many people voiced to me that that's what they were going to do and they declined testing because they didn't feel they were ready for the result at that time. And so, I think from our point of view, what we provided was a safe place for people to talk, a safe place for people to get information. We had the ability to refer people for other health issues. So, it was – we tried to keep it a safe contact point, thinking that a person might not be ready to talk to their doctor about this. So, we just needed to be a safe place for people to come, so that's where we started – where it all began for me.

BK: So, part of this complex decision making around getting tested was, "What good will it do me if I am positive? There is nothing I can do if I am positive."

DS: Okay, but we would say, well, if you were HIV positive we can tell you that eating properly will help your immune system. Getting lots of rest will help your immune system. Physical activity will help your immune system. And I do remember telling one young man all of those three things, and he looked me straight in the eye and said, "How much of that stuff do you believe and how much are you just telling me because it makes you feel better?" And I said – he fortunately was coming back for his result in two weeks – it was taking two weeks for the results. Imagine how stressful that was. And I thought to myself, "I have two weeks to find out the answer to those three questions." So, I talked to a nutritionist, I talked to an exercise therapist. I found they both said, yes, that helps immune system if you can keep healthy – really that's all we could tell people: we could tell people how to prevent getting infected as best we knew, how to prevent passing HIV along if they were HIV positive, and how to stay as healthy as possible if they were HIV positive and where to get care. And so, fortunately – lucky for me, he came back, got his result and I said, "Do you remember the conversation we had about…" [laughs] And he said, "No." And I said, "Well, I told you this, this and this. And you said how much did I believe, and how much was I just telling you because it made me feel better. And I want you to know you that you nailed it. I followed those up and all those folks said that that is good advice." And those are lessons that many care providers will tell you they learned from patients – it's the clients who will tell you something that will trigger you to go back to your books where you will look up and find the answers. And also, I think for me what it did is it told me that he picked up, as young as he was, that I didn't believe 100% and at that time it was important that I believed 100% and I came across that way. So, a huge gift from a young person.

BK: And to me, that would also speak to the degree of comfort in that interaction with a health care provider – saying, "Are you bullshitting me?"

DS: Yeah, huge! Huge. And he was young. He was, I would say, between eighteen and twenty.

BK: So, that sense of "I am not sure if this is really going to help me if I am HIV positive because I don't know what I am going to do for my health." And also, I guess HIV stigma probably played into that as well – deciding whether I wanted to be tested or not.

DS: People were being extremely cautious about who they would tell. It was a different world – it was a different world than what we live in now. I think people are cautious, and rightly so, now that they have a communicable disease. I mean, I don't think people go around and broadcast that they have syphilis and I mean with HIV they are possibly more cautious about who they decide to tell, but in those days in 1986 people were losing their jobs at work if they – or had a perception that they could be fired if they disclosed that there were HIV positive. And of course, they were missing work if they were sick and they had to have doctors' reasons and they were worried about the doctor saying why they were sick, why they were missing work. You know, it was a different time – it was a totally different world. Well, it was different world than what we have now – it wasn't totally different I think. I think people still worry a wee bit or more.

BK: So, who were these people that were coming to the clinic predominantly? Was it certain groups? Was it mostly young gay men? Was it…?

DS: No, it was mostly gay and bisexual men and some woman and woman who were working in the sex trade. I don't remember very many people who were disclosing that their risk was sharing needles in those early years. Most of the publicity around HIV was focused on the gay community. Many gay men had doctors that they went to for testing. Some gay men didn't have doctors and lots of straight people decided not to talk to their doctor because maybe they were bi[sexual] and they just weren't comfortable bringing up that topic. And we also – I remember having clients tell me that they would ask their doctor about a HIV test and their doctor would say, "Oh, you don't need an HIV test." That was quite a common sentence that people would ask us – would mention and so that's why they would come to the clinic. They might say, "I have a doctor but the doctor said I didn't need an HIV test, and so, here I am," because they think they did! [laughs]

BK: So, there was this sense that if you weren't in a certain risk group then maybe you didn't need to worry about it.

DS: I think that's true. And maybe there were – maybe they didn't want to disclose why they felt they may have been exposed to HIV and so they just opted to find a clinic. And that was why Mike Rekart set up the clinic in the first place – he wanted there to be – he felt it was important that Vancouver had a place where people could get tested, but could also talk to somebody and have a frank discussion that was confidential about how they might prevent getting HIV. But that's a public health, you know – public health's approach is usually try to prevent. Prevention is huge – prevention and accurate education. So, doctors where giving accurate education but people weren't necessarily accessing it from their doctors, so setting it up in Vancouver was our opportunity to provide a place where people could be safe. And when they came to collect their results, their file was just under the code number that we had assigned them which they had a copy of, and the only way the result could be linked was for that person to produce a card that had a number on it which would match the coded file. So, they, I think, felt comfortable because we weren't collecting their medical numbers, we weren't collecting addresses and phone numbers. And therefore, we could not notify a person that they hadn't picked up their result and so we had HIV+ results in our file cabinet that had never been claimed.

BK: Was that quite common?

DS: No, it wasn't common but it occurred, because it took a huge amount of courage to get that test at a time when there was no treatment. I mean, that person who chose to test was taking a leap of faith, and so I'm – I'm not surprised that people… The people who didn't collect their results I expect eventually found out their HIV status because they would have gotten sick and had to go to the doctor and perhaps got a test done through the doctor, or they may have come back into our clinic under a different name and a new number, and… So, we don't know – that's how anonymous it was or how confident- - I would call it confidential because to me you're not anonymous as long as somebody saw your face.

BK: This idea that people wouldn't be able to get a test from their doctor because they didn't fall into a risk category, it just speaks to the different levels of stigma that were operating. I mean, if you were a straight man who was having sex with men sometimes, how do you have that conversation with your doctor, right?

DS: Well, I think some of those men had that conversation with their doctor and had good results. But some might have – I can think of several who just felt that they weren't ready to have that conversation with their physician, so going to a public health clinic worked for them. And they would subsequently – anyone in the clinic who tested positive was invited back as many times as they needed to come back, and sometimes they would bring partners or brothers or sisters, just to talk about next steps. And we would just help them as best we could, usually to try and help convince them – to help them hook up with a physician was important, but we would never follow that up to see if this person went to the doctor. We would leave that up to them.

BK: So getting people into care?

DS: We really wanted to get people into care, for personal supports and for whatever medical support they needed. AIDS Vancouver had just opened, which was lucky for us because we could refer people to AIDS Vancouver. And in those days AIDS Vancouver had a service where they not only helped people who were newly diagnosed with HIV, but they would also help parents anonymously hook up with other parents through telephone calls. So, if a family member in Nelson expressed that their son was HIV positive – they would like to talk to somebody else who is going through that same experience. And AIDS Vancouver would talk to them, but they would also try to hook them up with a family who was willing to exchange phone numbers so that they could talk to each other, because in those day I believe most families whose sons were infected with HIV – many families didn't tell other people. So, they would turn to AIDS Vancouver, which was probably the first service or organization in B.C. that was dealing with HIV – they would turn to them.

BK: I hadn't heard of that program. That's amazing.

DS: That's fabulous. So, I often think that AIDS Vancouver jumped in before public health had a chance to respond, before hospitals – you know, before we could supply the social services people needed. Thank goodness AIDS Vancouver did. That's why I think it would be interesting for your team to talk to somebody who might have been involved in those early years. And then AIDS Vancouver split off into BCPWA but I don't even know when that was.

BK: And at that time did you start referring people to BCPWA?

DS: Yeah, if it was a person living with HIV, then BCPWA started to take those clients and had the expertise, but in those early years we were sure glad we had AIDS Vancouver to refer people to.

BK: Was the buddy program a thing then to?

DS: I don't know when they started the buddy program. That was – I have heard of buddy programs in African countries and I am more aware of what they offered. I can't really speak to what the buddy program at BCPWA offered.

BK: I guess I am just curious what support and care aspects of those organizations looked like.

DS: Actually, I think I know a little bit about that because AIDS Vancouver would have done one-on-one counselling. They ventured eventually into some groups but that took a lot of courage because people didn't want to come out about their HIV status, so I expect initially they were being quite cautious and perhaps not even meeting people in their offices. They may have been meeting people elsewhere, maybe doing – I don't know where, but there was… I think understanding the stigma, which I am sure you're aware of – understanding the stigma in Vancouver with an HIV diagnosis, everybody needed to be cautious. And AIDS Vancouver wasn't necessarily talking to public health and public health wasn't necessarily talking to AIDS Vancouver. It took a while for those relationships to solidify before they could all be on the same team, all working for the same purpose. And then you have to sprinkle in that the government of B.C. – that we needed to – Mike Rekart needed to sort of bring the politicians up to scratch to what was having with HIV.

So, there was – this was an emerging epidemic. No one knew how big it was going to become and it was affecting mainly one community, a community that was highly stigmatized, but luckily highly educated and luckily a community who quickly bonded together with a response which was huge. It was huge. You know, that gay community – had it been any other community that would have been affected first, I am not sure if things would have moved as quickly. But the gay community rallied – there was such a solidarity that they – they were just an example of how you move governments, how you move public health, how you move systems. And I think it was because they were motivated, educated, and had a kinship with each other that they – they needed to be together on this. And lucky for public health, because the gay community moved things along much faster than we would have.

BK: Yeah. Having studied this for a long time and thought about it for a long time, I always wonder what was it about this community that made it so resilient. And that's not to say there wasn't a tremendous amount of loss and trauma in this process but my goodness the response was so strong.

DS: But it must be because they – the men had a common bond that – they knew that society did not embrace them 100% and they knew that there was a huge need… And so, I think solidarity describes it. And I think the nature of the men in Vancouver – that wanting to make a difference is what subsequently grew into the places like AIDS Vancouver and BCPWA – people willing to speak up, go public. I mean Peter Jepson-Young and the Dr. Peter Center, Tiko Kerr and the art community – men who had courage. We're lucky – we're lucky. And I think when we look at the infections that are now happening – well, that have been happening for many, many years in the intravenous drug-using community, it's a different community. There is solidarity there but maybe harder to mobilize because – I don't know. The gay community were able to mobilize – they were not only businessmen but they were probably – just through their education, through their athletic activities, through the contacts they had and their social world it was easier for them to mobilize I think. And I have talked to gay men who have sat down at dinner parties and talked about, "Well what are we going to do. What's going on here?" So, I think that for some reason – well, I guess for many reasons, the gay community were able to mobilize, and lucky for Vancouver they did. Plus, they were looking at the mobilization of men in other cities – the men stepped up, mobilized. San Francisco, same thing.

BK: Do you have a sense of who else was involved in that kind of response? Like gay men where obviously leading that response but did they have allies in that response?

DS: Well, I think so. I think there were lots of woman who were – who joined with the gay community, whether they were gay woman or straight woman, whether they were sisters or moms or aunts, friends. There was certainly that kind of support group. But then there were also a lot of people who didn't involve their families, so those folks were probably the ones who benefited the most from those support groups that were set up. And I guess access to talk to both men and women, because the AIDS service organizations and the HIV service organizations offered the opportunity to talk to both men and women.

BK: I am just trying to think about where we should go next. You eluded a little bit to the governmental response to talking about public health – Mike Rekart having to get the province on board with combatting the epidemic. Any thoughts on how the province was responding as a governmental body? Did you have any sense about what they were trying to do?

DS: I am trying to remember what the sticking points were. I can't remember whether it was just raising awareness or whether there were decisions that needed to be made. It was probably funding – I am sure it was funding. I think it would have been funding for service organizations – increased funding for public health to be able to offer HIV testing through the province, increased funding to put out information about prevention. I think it would have started with those kinds of basics and needing to get the government to put their shoulders behind increased funding. So, I expect the first issue was getting people to understand – getting politicians to understand what the issues were, and some politicians may have needed some extra persuasion because this was the gay community, a stigmatized community. So, I think Mike Rekart had his work cut out for him, but he was fearless and he would jump in and ask for forgiveness after.

And I think he moved things quite quickly. And he had come from California – he had seen what was happening in California. He knew the urgency, he felt the urgency. So, those early years, he had to fight for funding.

BK: It's interesting to think of people in those more institutionalized roles playing these activist roles as well. It's not just gay men on the ground, it's also people in the public health sector.

DS: Good point. It took effort from lots of people. And even the city of Vancouver got on board, and they decided to – the biggest issue for them was addressing homophobia. So, the city of Vancouver's response was to hire a contractor who was a sexual educator. Her name was Meg Hickling. She was a nurse who had done a lot of sexual education with young people and was also a private contractor. So, the city of Vancouver hired her to set up a program that would address homophobia and every city of Vancouver employee needed to participate in this workshop. And the workshops were three to four – how many sessions were they? I can't remember how many but she recruited, say twenty of us, and into the hat there was a piece of paper with every department in the city of Vancouver, and all 20 of us picked randomly – picked which department we were going to be assigned to. Mine was the city of Vancouver detectives, so for every Thursday I would face a room full of detectives in the police station who – and talk about homophobia. And they had to be there – they had to attend – so it was a room full of men and woman, some were interested to be there, some were resistant to be there. And we had a curriculum and we all had to teach the same curriculum and be available to answer questions about HIV if they came up – just an interesting side bit.

BK: That is interesting. That sounds like a tough crowd.

DS: It was terrifying. It was probably the most stress – I did a lot of HIV education in my career and I would think that – that was baptism by fire, because I would have men saying, "Well, I can tell you there are no gay men in the Vancouver police department." They would just say this in front of the whole room, and I would see men looking at me going… [pause] and some of them would come up afterwards and I would say, "Well, now you know who's back – who you have to watch out for here." It was really – the worst thing I did, and this is not necessarily for your research project as it has no bearing at all but it's kind of funny. The woman who would prepare the room for me to do the lecture was terrifying. She was very officious – she explained to me that she had a brand-new whiteboard that she put in this room for this session and did I know there are two types of pens – there was also a flip chart – and did I know the difference between the pens you use on the board and on the flipchart. Yes, I did. Okay. So, then we start and for some reason, who know why, in one of the sessions I felt the need – somebody asked the question "What part of the urethra is susceptible to an HIV virus," and so I drew this penis picking up the wrong pen. I am sure the question rattled me – picked up the wrong pen on the whiteboard and looked – at the end of the day, go to clean off the white board and of course the penis wouldn't get cleaned off. So, I am rubbing it and rubbing it. So, finally I had to go to the woman who terrified me, and said I made a mistake with your white board. She came in and I thought she was going to have a heart attack. Anyway, every Thursday after that when I had to go back I could see this penis on the white board – everyone in the class could see it as well, so I just ended up telling everybody after that. So, that sort of opened up the conversation – any education, any group was easy after that one. Anyway, so moving on.

BK: Thank you for sharing that. So, you mentioned that there weren't a lot of great sources out there unless you were reading medical literature. Do you have a sense of what kind of sources gay men where using to educate themselves about the epidemic besides coming to you?

DS: Well they were talking to each other and they were probably reading the newspaper, and the newspaper could be confusing depending who was reporting. I am trying to think where else people were getting information – places like – we had the *Georgia Straight* in those days and there would be articles in the *Straight*. But I think in those early years there was – people still weren't sure about saliva – did Saliva transfer HIV? And what kind of condoms – you know, natural condoms or latex condoms? And I think there were those kinds of questions. And how many times do I have to be exposed to HIV before I get infected? And I think those were the kind of questions that we tried to answer, and we would go back to science and we would say this is what they currently think. And that's really the best we could do. And in those early years when there was no treatment, and I think those were the hardest years when there was no treatment – men who were diagnosed with HIV pretty well felt there was no hope and how were they going to frame the rest of their lives with this diagnosis. Then along came AZT and then the rest is history. But there were years when testing was available and before there was some treatment and I think that was sort of the most critical piece for men. Because it was mainly men – I can't recall testing any woman during that time but I may have.

BK: So how did you take that really complex medical knowledge and bring that to an audience who wasn't as aware of some of these medicalized terms. What did these conversations look like when you were talking to gay men?

DS: Well, I always found it easiest to start from what they knew and then to kind of evolve that way, and that gave me an idea of the language that they liked to use. And it gave me an idea of their understanding. So, I could fit the information that I knew into hopefully a framework that they could hear. So, I think most care providers tried to individualize their approach depending on who they were sitting with. Some people needed a real scientific approach which might mean that I had to make another appointment with them – ask them to come back and I would bring materials for them, or when I had a chance to refer and look up references for them. But most people really just wanted what's the latest information that you understand about how this transmits and how can I prevent transmission. And it's not a matter of – I mean we did condom demonstrations and things like that, but it's more a matter, I felt, of helping people negotiate condom use. That was – I mean anybody can figure out how to put a condom on, but it was more, "How do I ask my partner to use a condom" – men and women. But that conversation was much bigger then, once people decided that, yes, they just wanted to talk about prevention. And so, when people came back for their results, there was – sometimes they wanted to sit down and talk but sometimes if they were negative they were just out of there. Usually if they were HIV+ it was a much longer conversation, but each one was different – each one was different but usually we would talk about prevention as part of the pretest conversation. And as I said, some people just came for the information and didn't test.

BK: Because this was a time when there weren't a lot of good sources of information. I mean, the position you were in was actually very powerful because not only where you one of the rare sources of information but also hopefully they will talk about this information with their friends.

DS: Well, hopefully. Hopefully – most people were reluctant to even carry information about HIV in public – they wouldn't even take a brochure. That's how worried people were about – so you know, they would have been cautious about who they talk to I expect. Yeah.

BK: Do you know if AIDS Vancouver was doing any work around this that you know of?

DS: Oh, they were doing a lot. They had some poster campaigns and they – they weren't hosting a – it took a few years for there to be like a workshop. But they must have had ads in places – gosh, I can't even remember – in places like the *Georgia Straight*. But it all depended on whether or not they had funding. They were operating out of an office that was maybe four times the size of this room, with four people and four desks with very little privacy. Their start up – I mean, I don't even know where they got funding to start up now that I think about it. It wasn't as if the government jumped up and said, "Oh your AIDS Vancouver." I mean somebody would have had the idea that they needed this organization – that's why I think it would be extremely important to remind us about how did AIDS Vancouver start – they have that in the archives. I would be interested to see.

BK: Yeah, I am a little curious. There is this medical knowledge, then these ideas about safer sex which I think in some ways are based on medical evidence but some of those ideas are also being cultivated in the community and not just in the medical realm. Is that something you can address?

DS: Were they colliding? They were. Yeah, I mean sure – sure, that would happen. You know, somebody would get information from a friend or partner – might be misinformation might be accurate information – I'm sure there was that. And then you mix in coercions and power dynamics, drugs, and you wonder who is making a safe decision. It wasn't an easy – it wasn't easy to navigate. I think men found it difficult – I think men found it difficult to have frank conversations about HIV in those years – probably not much different than now. It's difficult to have conversations, but I think at that time, yeah, people would be careful I think who they talked to and how they talked about it.

BK: At the beginning when you started in this role, you were seeing mostly gay and bisexual men. How long were you doing this work for?

DS: I did testing for – well, I worked at BCCDC for twenty-eight years and I would say eighteen of those I was doing testing and then a lot of education. Because what happened in BC was the other health authorities outside of Vancouver Coastal, which was called Vancouver Health I think at the time, wanted to offer HIV testing in their communities. So, they would host workshops. So, we developed a workshop to help nurses in a public health role to set up a clinic similar to ours, and each health authority is really there on separate – like a company. And so they could – there was no mandate that they had to do it our way, the way we did it. We would just pass along to them how we did it and what worked for us and they could figure out what would work for them in their sites. And so, a lot of my time was spent building workshops for other nurses and delivering those workshops in BC. Then I took a hiatus from BCCDC and worked more in many of the Canadian provinces with mostly small communities and some universities – just raising – just helping people to understand how to have a conversation with people about HIV prevention. How to talk to people about HIV testing so they were going into the testing with their eyes wide open, how to support people when they were negative, how to support them when they were positive – that kind of thing.

BK: The epidemic must have looked so different in a rural context.

DS: It was like Vancouver, sometimes. I think we got into a rhythm in Vancouver where there was support services and people were a little more on side with HIV people, were coping a little bit better supporting people with HIV. And then you would go to a small community and it was like rolling the clock back. So, they needed – those health care providers were feeling somewhat overwhelmed where they had to start – they had to start at the beginning. But I think that just seemed to be a very natural thing to do – to pass along information and experiences that we had bumped up against and see how that translated in smaller communities. And there were lots of situations – one in particular comes to mind where I travelled from a jet from YVR to a float plane to a canoe with a tarp over our heads to this community that was divided by a river. The Protestants had moved to one side of the community and the Catholics had moved to the other side of the river.

And so, the nurse that had brought me up there to talk about HIV had said everybody in the community – in the Catholic community gathers every evening for a service and the nurse had talked to the minister and said, “I am bringing a nurse up to talk about HIV and would you like her to talk to your congregation?” And the minister said “Yes, but I would like to talk to her first about what she is going to talk about.” So, then the nurse said, “I think I should invite the minister for the protestant congregation as well if we are going to have this conversation.” And he said, “That’s a good idea.” So, the four of us sat down and I talked about what I had planned to talk about and they both said “Okay, well we will let you know. We will give you a call later on tonight and we will tell you.” Both ministers agreed that this was good information for the community, but that’s an example of how iffy it was to even bring information to some communities.

They really wanted to know ahead of time what you were going to be talking about. Are you going to be talking about sex? How are you going to talk about sex? In one of those sessions in another community I had to do it with an interpreter, so what that meant was spending time ahead of time talking about everything I was going to talk about and making sure the interpreter could interpret it. And one of the things I remember that happened there was I needed to talk about sex itself – I used the word sex about protected and unprotected and I noticed the interpreter was really spending a lot of time. Every time I used the word sex, it seemed to take quite a long time for that person to translate it. So, I felt we needed to kind of have a break and I mentioned this to the translator and he said, "The problem is there isn't a work for sex in our language, so every time you use that word, I have to describe the entire act." And I said, "Oh, wish you told me that earlier. I could have modified." But those were the things that made every community different – every communities' needs were different, their reception to information in every community was different. The nurses in those communities usually needed to have permission to bring in a speaker. You used to have to try to rally the citizens of the community to come to hear the information. Now, how many people are going – that you or I know that would leave there nice and cozy houses and go out for a HIV educations session at 7pm at night? Who's going to do that? But people turned up. So, I think the illustration there is that it was hard to get information out to people. So, how could people prevent getting exposed to something like HIV if the information had never even reached them? And any information that had reached them might have been misinformation, so across the country we need to be thinking – we know what's happening in Vancouver but across the country there was misinformation about HIV and there was sort of this movement that lots of people were part of. It wasn't just me, I can tell you that. There were hundreds of people doing education.

BK: That was not just because of the stigma of HIV but also because people were busy doing other things or perceived they didn't have time to spend on that that sort of information.

DS: Well, number one, people were shy to talk about anything that had to do with sex and there was a perception of "I will never need to know about HIV. It will never be in this community" - people felt that way. Just like in Vancouver, when we hired Jack Forbes who was a physician from Zimbabwe – when we hired him as a pediatrician to come to Vancouver to work specifically on HIV, I remember thinking, do we need a pediatrician? Why are we going to need a pediatrician? But fortunately, people were looking globally and saying, "There are kids being born with HIV. We need to have a pediatric program." So, that was a growth process for me in Vancouver – understanding that, magnified that one hundred times in Canada. Provinces and communities, even cities like Kelowna and Penticton and Nelson and – they would be in the same position as – you know, where could people get an HIV test if they didn't feel comfortable going to their physician? So, that's where public health started offering HIV testing across the nation.

BK: So, as somebody who was in that role for so long, was it really perceptible when the HIV demographic started to shift – like, it wasn't just gay men, there were other groups coming in to get testing? Was that a stark thing or was it very gradual?

DS: I think it was very gradual, but it was – it's important to remember that when people got sick with HIV they may have got infected in a major city, but then they may have chosen to return to their small community. So, the small communities, whether they be First Nations communities or not, would then – just because the person was there, they would either choose to support that person… Some First Nations communities really rose to the occasion – celebrated that person coming home and then used the opportunity to educate people and others, but I think every situation was different. Some people describe going home and being not welcomed with open arms and returning to a city where they knew no one. There wasn't – but I think every time somebody had the courage to go home, that enhanced the information. And as you said earlier, one person tells another person. I don't think there was a "one size fits all" on that one – every city, every community, every family was different.

BK: And at the BCCDC, were the people coming in the door to be tested – did that change in an obvious way over time?

DS: The nature of HIV in the injection drug community, which was the community we needed to start to reach – that was why we needed to develop a street outreach program and that's what Paul Harris would have talked to you about, because he and his colleagues took the information to the streets rather than expecting people to come to BCCDC, which I think is a model that was probably used around the world – but not designed here, but certainly was a successful one here. And they had clinics – the street nurses had clinics downtown, but they could also walk and do testing in people's rooms and also give them care – wound care. So, it was – no, I think the gay men would have cars – they could get themselves to BCCDC or go to their doctors. I – our perception was that we needed to take the services to other communities. That could have been because we didn't have a lot of clients that had come to the clinic. As a STI clinic they may – that might have been our first inclination, that we might have to look at a different way of delivering care, but the city of Vancouver was also providing care downtown. Different – there was a time when there seemed to be a lot of service organizations, so many that sometimes the right hand didn't know what the left hand was doing. I think that happens often.

BK: The communities that end up the most impacted by the epidemic in Vancouver and BC, most of them we would probably refer to as marginalized communities in some shape or form but marginalized in very different ways, and therefore different solutions are required.

DS: Mhm, I think you would get a really good sense of that if you ever get a chance to talk to Maxine Davis about the Dr. Peter center. To my understanding, the Dr. Peter Centre clientele evolved from mainly gay men, and then as the infection started to show up in the injection drug community, then the populations were different. And how did that work? Did those two populations blend or did they have difficulty blending in one facility? And I think that would be interesting.

BK: Absolutely. I think the same thing happened to some extent to the BCPWA coalition. So yeah, that's really interesting.

DS: Suddenly you're blending two communities…

BK: Who wouldn't be in the same room otherwise.

DS: No, but the other strange thing that happened is they may not as communities be in the same room but there is lots of gay men who inject drugs, and there is lots of injection drug users who may be gay men. But it took a while for the blending I think, or maybe it never happened – I don't know. But they would have an interesting perception on that social perspective.

BK: So, returning a little bit to you on a more personal level – this must have been a very emotional work for you, or a very heavy ex-…

DS: It was heavy. It was heavy and it took its toll. I remember feeling this – periods of sadness where – where you're sort of thinking, "Where is this coming from? Is this coming from my work or is this coming from just being a mum with young kids and being tired?" But one of the things that we did at BCCDC was we started to – at first, I was just doing the testing and over time all the nurses were doing the testing. So, we developed a policy – we had a policy in the clinic that the supervisor would know if any nurse was giving a reactive HIV result that day and somebody would check in with that nurse every time that happened so that we – because we began to realize that – after we talked in meetings – that there was a personal toll that was happening. So, we needed to watch out for each other and to make sure people weren't getting fatigued. We even hired a psychologist who could – actually that's another person you could talk to – Bill Coleman. We hired Bill Coleman to be a resource for our staff and to also be a resource for people we had diagnosed, which was huge. I don't even remember what year that was, but he would know when he came on board. But that was really helpful, just to know that there was somebody there.

BK: So, these were some of the ways you could avoid burning out? Avoid being crushed by…

DS: That – of course that only works if the care provider is prepared to go and talk to somebody. But what we did with – what we felt was we at least needed to connect with each nurse and see how that person was doing. And I expect Paul's group did the same thing. They were working remotely from BCCDC – they had a couple of clinics in different parts of the city, but that had one in the gay and lesbian community centre. And I think they would have done the same thing, they would have been trying their best to look after each other.

BK: Yeah, burnout is something that happened to a lot of people during the epidemic. I guess Paul mentioned that as demanding as his work was it also gave one's life a lot of purpose.

DS: Oh it was huge! It was – I think many of us had talked about – reflecting on what an honour it was to go through the different stages with clients, whether they be trying to keep themselves negative or trying to cope with what life is going to look like moving forward being HIV positive. And you really do feel that it is an honor to be able to work with somebody at that stage of their lives and for people to let us in – you know it's huge, it's huge. They didn't know us, we were strangers. Maybe because we were strangers was why the relationship started up in the beginning, and then only if we were good at what we did. Maybe if not – if we were good at what we did, but if we reached the person, those people might have invited us into to sort of continue to work with them. And I think the regrets I would have had as a healthcare provider would have been the times I didn't connect with the person – never saw them again, wondered sort of how did their life – you know, what happened? But we had to learn to live with that too, that some people just didn't come back – they didn't need any more help. You know, maybe they found another care provider that they connected with, but that's the life of a healthcare provider – you know, you're not going to be the right person for everybody.

BK: When did the meaning of HIV start to evolve? Initially, there weren't treatments. Some people would say you basically were giving people a death sentence when you told them they were positive, and then AZT arrives. How did that shift the way you provided care?

DS: It made it easier for the healthcare providers, yeah, but at the same time we were all well-aware that people were struggling with pill counts. In the early treatment days – and I don't know if you talked to people about what their dose of medications was like. Did you have a chance to talk to anybody about watches they had? Special watches that they had to program every two hours – take these ones on an empty stomach, take these two after you have something to eat, keep these ones in the fridge. It's not – that's not easy. I mean, I have trouble taking antibiotics on a regular basis for seven days let alone a lifetime of thinking I have to take these medications. And these medications made people feel sick, feel nauseous, feel dizzy, and they kept taking them – such a commitment to keep taking them, and they did. They kept taking them, and the pill regiment was very complicated. And I think you have to be thinking, "Where do I keep these in my apartment? Where do I keep them where I don't want anyone to see them? Do I hide them away?"

So, people were facing that – that they may have partners who use their washroom – had they discussed their HIV status with that person? Did they want people who come for coffee to see their medications? And some of these medications were kept in the fridge, so where do you…? I mean, it was difficult – it was a very difficult time. And I remember somebody telling me, that he felt that because he had to take his medication so frequently that he had no HIV downtime, and I said, "What do you mean by that?" And he said, "I don't have very many hours in the day where I am not reminded of HIV." And I thought, "Oh my gosh, that's huge." And that's – I can't say that that's different then now, but I bet people who are taking what's prescribed now might not have that same perspective – they might see their world as easier.

BK: Yea, we have definitely had people articulate that. A lot of people today, it's one pill – it's amazing. But even in 1996, some of the pills that people were taking were huge and they had to blend them up. It meant horrible gut issues.

DS: Yea, terrible. And feeling terrible when they take them and thinking, "Why am I doing this, and what's my prognosis going to be at the end of the day, or at the end of five years of taking these pills?" I think it's interesting to have lived through that to sort of see it evolve to the successful treatment where we are now and how hopeful people are, and it's good to remember back to how difficult it was. It was difficult when there was no treatment but it was early treatment that was so complicated and took such maneuverability, and that's difficult for people because people were trying to get back to work – not disclosing their HIV status at work. But feeling pretty crummy after they took a pill at a certain time of the day and not being able to take their lunch hour when they were supposed to take their lunch hour because that didn't fit in with their pills – I mean terribly complicated.

BK: And then some of those early treatment might not even extend your life by that much, if at all.

DS: No, that's right. "For what? Why am I doing this?"

BK: Do you remember when you felt for the first time that there's something effective now? To echo your patient who called you on your bullshit, "Are you telling me the truth?" Do you remember when you actually started to believe that some of these things are going to help people? Was there a moment when that happened?

DS: [pause]

BK: I mean, does 1996 stand out as a big moment in your mind?

DS: Oh, you mean because of the conference here - the 1996 conference? Yes, of course we were hopeful. I don't think I really felt that we were on the right track until I started to hear that the pill count had been cut down to a simpler regiment and people were voicing they didn't have as many side effects, because I think at that point – I then think about science has to produce a pill that people can take and not feel – and that they will take it. And so, I think I didn't really feel to hopeful until it was simplified. I can't even tell you what year that was when it was simplified, but that would have been for me personally, because I really empathized with people who had these complicated regimens and how sick they were feeling just from side effects.

BK: And long-term kidney issues and-

DS: Oh, everything – like neuropathy!

BK: Not small problems.

DS: No, no.

BK: And I guess on an even larger scale, how has your perspective on HIV as a healthcare provider and as a caregiver changed over time looking long duration? We have been articulating that for the last couple minutes, but from the start of the epidemic to our present moment is there…

DS: Well, for me, I branched into education and wasn't doing as much testing near the end of my career, but I can imagine – I do remember that once there was treatment, it was easier for me to give an HIV diagnosis but not easier – probably not much easier for the person hearing it. The interesting thing about nursing is that before HIV there was – nurses weren't ever the person to diagnose let's say a terminal illness – that was never a nursing position, that was a physician's position. So, it was an unusual world for us to be in as nurses, to be diagnosing a condition that was so serious. We weren't alone – we could refer that person to physicians, but it was an unusual territory for nurses to be in. But personally, it became different when we could say to people – when I could say to people, "There is treatment now and people are doing well" – when I was able to say, "The science tells us if you take these medications you're going to live. You're likely not going to die of HIV. You may die of something else, like old age." But that was different, there, the range from, "There's not really very much, except we can support you," to, "You can move forward with this." I don't think it minimizes the impact – I mean I think people – still, there is an impact of receiving an HIV diagnosis, but it's maybe hopefully very different than it was in the 1980s.

BK: Another kind of large scale question: how do you think the epidemic changed or influenced the shape of the gay community in Vancouver? Do you have any thoughts on that?

DS: Well, not being a member of the gay community, I don't think I can speak to that – I expect some of the men that you are interviewing can speak to it, but I don't think I should be speaking to that. I would have perceptions. I think that the one – there's a troublesome perception, but it's a health one not a social one, and that would be that now that HIV has become a treatable infection and our syphilis rates are going up – syphilis is, while treatable, a nasty one to have and the side effects of some of the complications for syphilis are huge. And it seems like worldwide there is a syphilis epidemic. Is it tied to unprotected sex and the fact that HIV is treatable? Probably loosely, which is a hard one for the gay community to wrap their head around, I think. I think it could be quite divisive.

BK: Well, kind of leading off of that, do you have any advice for healthcare providers in the present for how prevention could be improved, care could be improved, interventions of various kinds can be improved?

DS: [Pause] I could say that there was a time where I felt that we needed to put more information out there in places – this is before you saw things in bus stops. I would have put it on billboards and put the information out more where it could be seen, and I remember speaking to that issue to people who would have had the power to do that, and them saying, "There's only this amount of money. Would you want us to put that into research, into testing, or into broadcasting messages?" Then it comes down to dollars. How many dollars and where are dollars best spent? Turning the clock back, would we have reached more people putting out more information in more public spaces? I don't know. And I have been away from the prevention front for long enough that I couldn't tell you whether it's changed. I expect a big change is that when we started HIV testing in 1986, we had the STI clinic and the nurses doing STI and then we had a specialized HIV clinic where you would just get an HIV test. It's kind of fuzzy to me now why we felt we needed to have the difference – I don't know why we felt we needed to make the difference. Now, of course, any nurse who's doing STI screening would also offer HIV. I mean it's so – so, I guess to go back to your question, we started one way and we evolved to making it more accessible, but I can't speak to how it's being done now. I expect – well, I don't know. I don't know how it's being done now.

BK: Yeah, I also wonder about, from a healthcare or research perspective, what can we do about the re-emergence of syphilis as an epidemic? And HIV is very much – amongst younger gay men, the rates are rising. These are very concerning things.

DS: Are the rates rising in young gay men?

BK: Yeah, they are.

DS: Men who have not lived through what the older men have lived through? And I have talked to men that had said they were afraid this would happen, because there was such an impact on the men who lived through those early years. Men who were in their twenties and thirties buried friends, you know, went to far too many memorial services or celebrations of life. So, there was an impact on those men. So then – I haven't looked at or seen the numbers recently, so I had no idea they are rising again. Wow, that's terrible – that's terribly sad to hear that. I knew the syphilis numbers were up but…

BK: Yeah, I think it must be related to differences in perceptions of what HIV means to people.

DS: Treatable disease, you mean? It's treatable.

BK: And if that's all you've ever known as a younger gay man, that this is not something you want to get but you're not going to die from it…

DS: No, you aren't going to die from it. Maybe would you have – I wonder if men feel there's less stigma. I don't know. Wow, that's not very – I am unhappy to hear that. So now we want to look at how will your research that you're doing – how can that be put out there to somehow have an impact?

BK: Yeah, that's a big part of it – how can we create this cross-generational dialogue that seems to not really be happening a lot?

DS: So, I have a question: are there young gay men who are acting as activists, as educators? Is there a movement out there in the bars? I mean, Paul and I are old folks, but Paul did a tremendous amount of work in the gay community. Are there young men stepping up and doing the same kind of prevention work in the gay community?

BK: I think there are, and I think YouthCO does a lot of amazing work. One of the questions I was going to also ask you was do you have any advice for younger gay men – this new generation of gay men who haven't lived through the epidemic? To advocate for your health?

DS: I think giving men and women the skills to negotiate what they want has got to be one of the key points where I would place my energies. Would be – I mean, everybody's different and everybody's needs are different, but helping people figure out how to negotiate what's going to work for them would be one place to start. And that's not easy because that is usually a private conversation – I mean, it's not something you're going to have in a bar. But we all learn from other people, so if one person can demonstrate to me how they got out of a difficult situation, I could listen to that and think, "Oh, I can say something like that. That might work for me," if that was important. But it's all tied into needs – emotional needs, physical needs – and sometimes our physical needs and our emotional needs supersede our intellectual responses. But to me, I would say that's one area where I think we could help people is help them to come up with some approaches that work for them and feel true to them.

BK: Yeah, that's a good one – empowering people to have agency over their own health and sexual decisions. I think I have asked most of the questions that I was hoping to cover in our time together. Was there anything that you wanted to talk about that you hadn't had a chance to address? You can take a moment to think about it.

DS: I don't think so. Hm, I don't think so. I think you've – I'm amazed you have been able to cover as much as you have. [laughs] You've done a good job. I don't think I have anything.

BK: Alright, well, I think we will just leave it at that then, and thank you so much for taking the time to share your story with us.

DS: You're welcome.