Challenges and Opportunities in Rural HIV Health – Q&A Session

Dr. Helmut Albrecht, Dr. Katherine Schafer, Dr. Lauren MacKenzie, Dr. Abu Hamour, Dr. Mona Loutfy, Dr. Stuart Skinner
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Helmut Albrecht: Maybe I'll start – Lauren how do you find your patients? How do you select them for your studies?

Lauren MacKenzie: In BC we're really lucky, we have lots of databases. For those studies we used the Drug Treatment Program database. That database captures anybody who has ever been prescribed antiretrovirals in British Columbia, which is a really helpful database to have and for our studies in particular, for our Programmatic Compliance Score we were looking at anyone who was antiretroviral naïve between 2000 and 2013 and so it ended up being about 4000 patients. We excluded anyone who had died within the first year and we included anyone who had had at least one plasma viral load and one CD4 count.

HA: But for your questionnaires the numbers were obviously much smaller and your rural numbers were particularly small.

LM: Yes, our rural numbers were quite small and I wonder if that has something to do with the definition. As you mentioned we get different numbers of rural people depending on what definition you use. Going forward we're going to look at a couple different definitions and try those out and see how they influence our results.

HA: Any questions from the audience?

Audience Question (1): Hi I'm Caitlin and I work in the pharmacy at St. Paul's. I was just wondering about the definitions that you used and why you chose those and if metropolitan influence zone is one you would explore or if that's not feasible at this time and why?

HA: Could you repeat the question briefly?

LM: Sure, I think the question is asking why we chose the rural definitions that we did and it mentioned specifically another rural definition and whether we're planning to use it in the future. So what we were hoping to do, based on some of the scant literature that's available in Canada was to use two types of definitions, one that divided people up into rural or urban, that's where we used postal code. We're also limited in terms of what types of location information we have in our database. That's why we used the postal code one. In terms of the general practice rurality index, we thought that one was kind of nice in that it captured things that other definitions, such as the MIZ, don't capture; so things like how many GPs are in the area? Whether there's a local hospital. Things like that, that might be more relevant to our patient population. The MIZ, or Metropolitan Influence Zone, that's the other definition we refer to, and that's one that we're looking at and there are also some Statistics Canada definitions that they use in the census that break things down into rural, small population

centre, medium population centre, large population centre. There are a lot of pros and cons to each of them, to be honest, so we'll see how it goes but those are definitely some that we're looking at.

Audience Question (2): Thanks to each of you for your amazing work and your presentations and the sharing of everything that's been going on in each of your worlds. I want to direct acknowledgement to Mona and Stuart in Saskatchewan. I think part of the high rates of HIV I've heard of quite a few times that the First Nations population is the highest rising in Canada, in Saskatchewan. Twenty years ago I was a First Nations child, youth, and family worker working here in the school supporting families. Part of what happens is the migration of people, often from the prairies to the Vancouver area because all year round it's good, a little bit better, weather. My question is aimed around transmission rates, is that, because I deal with a lot of people in the Downtown Eastside, that often migrate back to their home reserves. And sometimes when it's family issues, it's all around child protection, trying to stay away from those social workers who will move those children if they don't grab them and go back home to their reserves and stay there, then the problems arise there and they come back. Back and forth, back and forth. And I really feel that part of that contributes to the high rate of transmission. I'm just wondering if you support, what I've heard is that our young ones are having lots of young ones at high rates. But I thank each and every one of you and just to double up, I'm just wondering, I've been at Vancouver Native Health here in the Vancouver Downtown Eastside area and they run a peer support program and I'm just wondering if each one of you, all of you, I ask, in your journeys if they have any of those kind of things and I really feel that combining medical treatment with social services. So two things, your acknowledgement on what I feel about what is happening in Saskatchewan and for each one of you, what do you feel about peer support. This goes a long way towards getting those people into treatment. Haichka. Thank you.

Mona Loutfy: Thank you Elder Roberta for bringing that point. Saskatchewan is the province with the proportion of the population that is the highest to be First Nations, Metis and Inuit, and the rate is increasing higher than any other province. I think the prediction is that by 2030 25% of the population is going to be First Nations/Metis. Which I think is a good thing. But it does contribute to what's happening with HIV since there is a lot of intergenerational trauma. Saskatchewan was the last province to get rid of residential schools in 1996. There's a lot of migration, so when I said that the 20 cases in Prince Albert this year haven't been totally sorted out, there's migration from the First Nations communities to Prince Albert, to Saskatoon, Regina, to Vancouver, to Edmonton. There's a lot of migration all over. Both Stu and I have seen cases where HIV will be brought back to the First Nations communities and it's families that are affected. So it's mothers with daughters and cousins and uncles and aunts. I don't know if that's happening in other rural places, I'm sure in BC it is. The needle sharing happens with family members, so it's entire families that are infected with HIV which is also a unique phenomenon to the epidemic. So I didn't have it up as one of my issues but the migration is huge. I would think that child protection agencies point is really important. Probably the best location that I've seen deal with this is in Saskatoon. Steve Sanche is here from Saskatoon. What they did in Saskatoon, the public health has been working with the child protection agency to help keep

some of the children with the mothers and I think they even have a house where the women can go and detox and are supported to keep the children. So the women aren't running away anymore from the child protection agency and everyone is working together, so that's been really positive. I know that in Regina and Saskatoon you have peer programs, we're just starting one in Prince Albert and I've been trying to push for one in Ahtahkakoop but it's been slow going. But definitely peer support is so key.

Stuart Skinner: So Regina has a dedicated peer program. They do some outreach to some of the communities, so Krista Shore runs that program. Part of the challenge in the smaller communities is always the issue of stigma and confidentiality but one of the things we found was, if you provide a good service that word of mouth spreads and people all know each other. So then it's "hey, you know what, this program's running in the community and they're doing a pretty good job and you can get good treatment" so that word of mouth seems to spread directly person to person. I think we need to look at different peer programs into the smaller centres and mobility is a big challenge. The one thing that the two First Nations do is they stay connected with those patients no matter where they are so that really helps so that's why retention numbers are so significant. One of my experiences is that they move back, people moving back into the communities where we provide treatment programs and they feel safe in the communities as opposed to some of the big urban centres where there's less social support.

HA: Dr. Schafer and Dr. Hamour, do you want to comment on the peer issue?

Abu Hamour: Thank you very much for the question. Peer support is an integral part of HIV care provision. We have several advocacy groups that are operational. The most notable of which is Positive Living North. What's unique about Positive Living North as an organization is that it actually employs people who are living with HIV and AIDS. They act as life coaches for other patients and for families who support other patients. They are involved on a daily basis in care delivery and they help us with the adherence support program. They play a very important role in helping patients take medication, come to clinics, go to investigation appointments, and so on. So Elder Roberta, I totally agree with it.

Katherine Schafer: I also agree and wish that we had the peer support groups that have just been described in these other communities. Unfortunately, there are a couple that are offered through the AIDS support organizations in the community. One of them is in a town over thirty minutes away but most people, when we offer a support group, they don't want to go because they don't want people to know that they're positive. I would love to see more peer support and we've talked about maybe trying to have peer educators or peer supporters in the clinic to help escort people through the system, sort of like our patient navigators do, but on a more personal level. We're not there yet. If you are in Dr. Dillingham's discussion group she may talk to you about some really interesting work using a peer support group through a cell phone app, something that I think our patients would really warm up to because they would be able to have that confidentiality and access. Unfortunately, it hasn't taken off where I am.

HA: Of the seventy people that work in my group, twenty are peer counsellors or have peer positions. It's absolutely vital for any program. Where I work, probably 80% of my patients are African-American and I can send as many white docs in there as I want, it's only going to go so far. The one place it really makes a difference is in the adolescents. South Carolina also has the highest rate of adolescent HIV. It's a disaster. They are the most difficult group to keep in care. The only thing that we found worked is peer groups. One to one peers, actually, that bring them to the meetings and that has developed a community, almost, that works. There's an incredible program in South Africa in two of the cities that work with youth, that work with positive and HIV-negative peers, which I thought was a fabulous idea. That's even more difficult to arrange. I do think it's a vital part of any HIV program to keep adherence and linkage up. Any other questions?

Audience Question (3): I have one last question, I'm Rebecca Dillingham from the University of Virginia. I was so struck by the ways in which the colleagues from Saskatchewan and BC have engaged community leadership in the administration of your HIV programs. I'm also struck by the way we use the cascade amongst ourselves and I wonder if you have fed back your really incredible work to the community leadership and if so, how have you done that and what thoughts would you have about continuing that engagement with that leadership around the successes you have as well as using it as an opportunity to bring up continued challenges?

AH: We really rely on the team approach and integration of the care we provide with primary care. We can't really do this, especially in such a vast and great area. We couldn't possibly do this in the same way that Clarence has done, so we have to rely on really empowering care providers in a shared care model to deliver the goods and that entails a lot of education on integrated care and supporting public care providers especially in the area of screening and testing so that we can diagnose those who are undiagnosed and get them into care. Once they're diagnosed then really it's a matter of sharing care with the client and providers, with community support, with peer support, wherever we can involve the community. There are some communities that are more active than others in supporting people living with HIV but there are also a lot of issues around stigma that we have to deal with all the time. Those are, as you mentioned, more pronounced or more noticeable in the more rural areas. So really the combined team effort and approach, a multifaceted approach, is key to improving the numbers in the cascade of care a lot higher than the 68% that we have now.

ML: I want to pass it to Stu because the success wouldn't be possible without working with the community and no one's better at it, that I know, than Stu.

Stuart Skinner: In terms of engaging the communities and Chiefs it's taken a number of years and a lot of time but I can't speak enough to the community leaders and those Chiefs who take this on. They're incredible and inspiring and they just tackle this head on. I guess the biggest thing is about respect. I have a tremendous amount of respect for the First Nations, the challenges they face, the resiliency, what they're able to do with what they have. We're constantly communicating back and forth with leadership, if I'm going to give a presentation I'll say "is it ok?" and they say 'yup'. We had a meeting in Ottawa on Tuesday with the Federal

Health Minister's office and I had three chiefs come with me and I think at the end of the day, it's mutual respect and they know that when I speak about the community it's speaking about the successes and when we show those numbers that inspires them to say "look what we can do". It's not just HIV but we should be expecting the same with diabetes and high blood pressure, everything. It's mutual partnership.

HA: Are there any other urgent questions?

Audience Question (4): I don't need the mike. I'm Bob Hogg from Simon Fraser. Essentially, in Saskatchewan, is there any attempt to put together a health authority like we have here in BC for First Nations? What would the impact have in terms of the epidemic there? One other question, in terms of the epidemic, you're looking at communities that are halfway up, what about the other communities? Do you have any programs in terms of testing in those areas?

SS: So to answer the second question, Chris Stuart goes further up north, Kurt Williams as well, they go to La Ronge, which is a community of ten thousand people in the surrounding area. They have a program that runs there and that's in partnership with really strong family physicians. Then they also do, further north up in Ile-a-la-Crosse and La Loche, but the testing programs are long, you really need to keep up. He's out managing and supporting these patients in those communities. The further you go north the further the stigma is and especially in a small town like La Loche the stigma is, they won't even go to the health centre, it's so intense. So Chris is up north and I'm kind of out east in some eastern communities and central communities so in terms of programming, we've got lots of different sites where we're trying to provide more HIV and specialized care. In terms of the first question about the First Nations Health Authority I think that is the way we need to go, in that direction. I'm working with Saskatoon Tribal Council, which is seven communities and they represent twenty-three other communities about developing a mobile bridge where they would provide linkage of their communities into the urban centres, whether Saskatoon or Regina into a chronic disease centre. I think that's where it needs to go but I don't know how to build it towards that as it's very complex. If anyone is here from the First Nations Health Authority they'll understand the challenges a little bit. But I think that's the way we need to go.

ML: Being an outsider coming to Saskatchewan to see what's happening there's nothing really organized to address the rurality of the epidemic and what I've noticed is it's very hard working, front line people like Stu, like Christ Stuart, like Steve Sanche, like the nurses, like Clarence, like Suzanne and Chassidy, it's frontline people doing the work. But it's not organized. And I'm from outside so I can say that and I won't lose my job.

HA: Thank you, thank you to all the speakers.