Rural HIV – a *brief* overview

Dr. Katherine Schafer
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(Slide: Rural HIV – a *brief* overview)

Helmut Albrecht: So we'll start with the first presentation, it's by Katherine Schafer. Katherine is an assistant professor of medicine at Wake Forest in Winston-Salem, North Carolina where she serves as the HIV curriculum director for the ID fellowship. Katherine?

Katherine Schafer: Elder Roberta, I can totally relate to the microphone issues, usually needing a stool as well but I have heels on today. Thank you for that beautiful opening prayer, it was incredibly special. So I'll just cut right to it. I have the privilege today of giving a very brief overview to what is rural and what is rural HIV. My apologies in advance, this may be a little bit slanted towards data from the United States as I was able to access this data a bit more easily. But please don't take that as my lack of acknowledging the situation in Canada as well.

(Slide: Disclosures)

The only disclosure I have is that I am a site PI for a text messaging study through the Research Triangle Institute.

(Slide: Overview)

A brief overview of what I'm going to cover. I'm just going to go over some definitions of rural, then talk about what is the significance of rurality, why are we all sitting here today. A little bit about the epidemiology in the United States as a whole. I'll talk about rurality and engagement in care for people living with HIV. And then just some brief conclusions.

(Slide: What is rural?)

So the question 'What is rural?' We started talking about this probably two or three years ago actually and the long story short is that there really is no single definition. In the United States there's at least five different taxonomies. In Canada there's at least three. And that probably is in no way complete. The United States federal government uses two different taxonomies for rural depending on what office you go through. As you can see on one of the posters today there are two commonly used definitions for rural in Canadian HIV research. I think we would all agree that the definition of rural has both subjective and objective components. It's the subjective components that are, I think, the real heart of the matter and also very difficult to define. The objective components often come down to population size or distance from major metropolitan areas but as we all know it may not be too too far from a major metropolitan area but the community may be very rural in many ways. I think what's very significant is that there's no definition of rurality that applies across international borders and that has come up as a barrier in terms of doing research in rural HIV across borders.

(Slide: Why does it matter?)

So, why do we care? Well, I know I'm preaching to the choir as you specifically chose to spend your Saturday afternoon at a session on rural HIV but I have a few ideas based on what's in the literature.

There's tremendous health disparities for people living with HIV in rural areas, but also for people living without HIV in rural areas. There's less access to providers and technology. The quality of care may be different for various reasons. There are higher rates of cardiovascular disease and higher rates of suicide for males in particular in rural areas. There's also higher rates of tobacco abuse and traffic injuries. I would argue that HIV is becoming a health disparity that we're seeing in rural areas and as we're seeing the United States the epidemic is really blossoming in the southeastern part of the country, which Dr. Albrecht will talk about later. But that is a largely rural area now faced with the fastest growing numbers of new HIV diagnoses in our country.

There can be tremendous socioeconomic disparities in rural areas. In the United States there is lower per capita income per household compared to urban areas. Rural health care can be expensive. Now I recognize that there are different health care systems between the United States and Canada as well as many other places around the world. At least in the United States rural health care may be more expensive due to the lack of competitive forces to drive prices down. Travel can be very expensive, and that's true everywhere.

There's also significant challenges in recruiting and keeping providers. Again, true of Canada and the United States. It matters, at the end of the day, the data that we have is what informs policies and funding and if we don't have data on people living with HIV in rural areas then we can't enact policies and get funding to help support these people and their providers.

(Slide: Top Ten Barriers to Care)

There's a systematic review of studies in the United States that examined barriers to HIV care. These were the top ten barriers. Again, none of these will come as a surprise to those of us in the room.

Transportation and distance to care are major barriers for folks who are living in rural areas with HIV.

Confidentiality is a major one. I can't tell you how many times I've had patients ask me to send prescriptions to a pharmacy that's an extra ten miles away because they don't want to go to the local pharmacy where their cousin works or where somebody else works who may recognize them and find out that they have HIV.

Community stigma towards people with HIV but also provider discrimination and stigma. And that can be provider discrimination again people with HIV, that could also be stigma from the community toward providers who care for people with HIV. Stigma is a very multifaceted and multidimensional factor for our folks who are living with HIV in rural areas.

Certainly as I alluded to earlier there are financial barriers both in terms of insurance in our country but high costs of care, as I've discussed earlier, and there is a higher rate of problems with stable housing in rural areas as well.

As I mentioned earlier, there is often a challenge to having well trained health professionals in the field of HIV in rural areas. So often there is a pure lack of, or there's just inadequate training for how to care for HIV.

There's also very limited awareness of available services. We were speaking earlier about some of the ads that are on the bus stops here in town (Vancouver), how to find where your local HIV care is. We don't have anything like that where I live. And so there's not a lot of publicity about how to get care, where to get care, or where to get testing.

And denial, as many of us have seen denial plays a major role in the health of people living with HIV, particularly outside of major urban areas.

(Slide: Graph, Diagnoses of HIV Infection among Adults and Adolescents, by Population of Area of Residence and age at Diagnosis, 2011 – United States)

These are some data from the Centres for Disease Control and Prevention. They show the diagnoses of HIV infection among adults and adolescents by the population area in 2011. On the X-axis is the population size. All the way over here (left side of graph) is urban areas, so the metropolitan statistical area greater than five hundred thousand people. On the far right are the nonmetropolitan, or rural, areas. The coloured bars are for age ranges. On the Y-axis is the percentage of new diagnoses. Now the main take home point here is that there are similar age distributions regardless of whether somebody lives in a rural or urban setting.

(Slide: Graph – Percentage of Stage 3 (AIDS) Classifications among Adults and Adolescents with HIV Infection, by Population Area of Residence, 1985-2011 – United States)

This slide also shows data from the CDC with percentages of AIDS classifications among adults and adolescents. The orange line is what we would say is an urban population and the light blue line is rural. The take home point here is there has been a slight increase in AIDS diagnoses in nonmetropolitan and smaller metropolitan areas in the United States.

(Slide: Engagement in care in rural settings)

So engagement in care is a major issue for people living with HIV. How is it impacted living in rural settings? Well, it's negative, unfortunately. Rural residence is associated with a negative impact across the cascade of care. There's less testing. There's delayed linkage. There's delayed start of antiretroviral therapy. Medication adherence may be worse. There's higher mortality. There's also data from Mike Ohl that showed that distance to care was directly related to visit attendance so the farther somebody lived from their care provider the less likely they were to attend clinic visits.

(Slide: Lower frequency of HIV testing in rural vs. urban U.S.)
Briefly, these data show what I mentioned about HIV testing. People who live in rural areas are less likely to report lifetime testing or testing in the past year.

(Slide: Rural residence is associated with lower survival after care entry)
These data represent that rural residence is associated with lower survival after care entry. So the blue line are people with HIV in rural areas, the red line is urban. As you can see, they have lower survival over time.

(Slide: Conclusions)
So in conclusion, there is a lack of clear definition for rurality, and that may be impeding research, policy and funding issues. Rural residence is associated with worse engagement across the cascade of care. We need to discuss innovative approaches to how to meet the needs across the cascade and setting of rural residence.

(Slide: Acknowledgements)
I'd just like to thank our patients, who teach me everyday about how important this issue is; the session co-organizers who worked so hard; our speakers, facilitators and you, the attendees; CANOC for providing support for this event; and the members of the North American Rural HIV Working Group. Thank you.