Original Article

Building More Bridges: Indigenous leadership in a study assessing the impact of distance to care on markers of quality HIV care in Saskatchewan

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See Figure 1 for Authorship Circle

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Abstract

Introduction: Individuals in rural and remote areas face barriers to chronic disease care, including HIV. Saskatchewan has the highest HIV incidence among Canadian provinces and 35.6% of the population lives outside of an urban centre. In this study, we explored the relationship between distance to HIV care and markers of quality HIV care in Saskatchewan as part of the Canadian Observational HIV Cohort (CANOC).

Methods: We used a Two-Eyed Seeing approach and honoured the experience of Indigenous team members living with HIV. The Positive Partnership Score (PPS) was the primary outcome (including frequency of viral load and CD4 measurements, baseline CD4 count, antiretroviral medication regimen and virologic suppression). Multivariable linear regression analysis was performed with distance to care defined in two ways: (1) categorical based on distance from home to HIV specialist care and (2) road distance from CANOC enrolment site.

Results: Two hundred and seventy-six individuals were included in the analyses. Living ≤25 km from a visiting HIV specialist (where no HIV specialist lives in the community permanently) and living >100 km from the closest HIV specialist (either visiting or permanent) were both associated with lower PPS compared to living ≤25 km from where an HIV specialist practises permanently. Each 10 km further from the CANOC enrolment site was associated with a 0.01-point reduction (95% CI-0.02, 0, $P = 0.024$) in PPS.

Conclusion: Through a strength-based approach that was grounded in culture, connection, land and Ceremony, we demonstrated how Indigenous people with HIV can play a key role in research. Distance from care was associated with a poorer quality of HIV care in Saskatchewan highlighting the need for better rural HIV care.

Keywords: Distance to care, HIV, Indigenous leadership, Saskatchewan

Résumé

Introduction: Les personnes vivant dans les régions rurales et éloignées sont confrontées à des obstacles aux soins des maladies chroniques, y compris le VIH. La

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Saskatchewan a l'incidence du VIH la plus élevée parmi les provinces canadiennes et 35,6% de la population vit en dehors d'un centre urbain. Dans cette étude, nous avons exploré le lien entre la distance aux soins du VIH et les marqueurs de la qualité des soins du VIH en Saskatchewan dans le cadre de la Canadian Observational HIV Cohort (CANOC).

Méthodes: Nous avons utilisé l'approche de « regard des deux yeux » et honoré l'expérience des membres autochtones de l'équipe vivant avec le VIH. Le score de partenariat positif (SPP/PPS) était le résultat primaire (incluant la fréquence des mesures de la charge virale et des CD4, le nombre de CD4 de base, le régime de médicaments antirétroviraux et la suppression virologique). Une analyse de régression linéaire multivariable a été effectuée avec la distance aux soins définie de deux manières: 1) catégorique, basée sur la distance entre le domicile et les soins d'un spécialiste du VIH, et 2) distance routière du site d'inscription au CANOC.

Résultats: 276 individus ont été inclus dans les analyses. Le fait de vivre à ≤25 km d'un spécialiste du VIH en visite (lorsqu'aucun spécialiste du VIH ne vit en permanence dans la collectivité) et le fait de vivre à >100 km du spécialiste du VIH le plus proche (en visite ou en permanence) étaient tous deux associés à un SPP plus faible par rapport au fait de vivre à ≤25 km du lieu où un spécialiste du VIH exerce en permanence. Chaque tranche de 10 km plus éloignée du site d'inscription de CANOC était associée à une réduction de 0,01 point (IC 95%:-0,02, 0, P = 0,024) du PPS.

Conclusion: Grâce à une approche fondée sur les forces et ancrée dans la culture, les liens, la terre et les cérémonies, nous avons démontré comment les autochtones atteints du VIH peuvent jouer un rôle clé dans la recherche. La distance par rapport aux soins était associée à une moins bonne qualité des soins du VIH en Saskatchewan, ce qui souligne la nécessité d'améliorer les soins du VIH en milieu rural.

Mots-clés: VIH, Saskatchewan, leadership autochtone, distance par rapport aux soins

INTRODUCTION

In Canada, individuals living in rural and remote regions have higher all-cause mortality, incidence of injury and prevalence of many chronic conditions.[1-5] Difficulty in accessing health-care services, which is reported by over 50% of people in rural Canada, may contribute to these discrepancies.[1-5] Rural communities are frequently impacted by significant physician and nurse shortages, limited access to screening and diagnostic programmes and higher emergency department and hospitalisation rates compared to urban areas.[1,6,7] A significant barrier to care is having to travel long distances to access services, which is exacerbated by limited transportation options, associated costs and inflexible hours of operation.[1,6-11]

Associations between access in rural settings and HIV-specific outcomes have also been noted, such as lower testing rates, later diagnosis, delayed linkage to care, lower treatment uptake and poorer clinical markers of HIV care.[12] Additional barriers to rural HIV care include HIV-related stigma and confidentiality concerns, limited community and provider HIV education and a lack of HIV services such as specialists, peer programmes and other social support services.[10,12-14]

In 2018, there were roughly 62,050 people living with HIV in Canada, and rates of new diagnosis increased by 8.2% compared to 2017.[15] Of these individuals, 85% were receiving antiretroviral therapy (ART), which is essential to reduce disease progression, including death and prevent HIV transmission.[16-18]

Saskatchewan has the highest HIV incidence amongst Canadian provinces with HIV transmission rates nearly double the Canadian average.[15,19] However, only two major cities have multidisciplinary HIV clinics which may not be accessible to the 35.6% of the Saskatchewan population living outside of an urban centre.[20] Although a few visiting HIV specialists provide care in smaller/remote communities, there is a lack of HIV-specific care, peer support and HIV educational resources available – particularly in rural/remote Indigenous communities where HIV transmission is high.[21] HIV-related stigma, discrimination and racism are rampant. These barriers, coupled with long travel distances to services, are significant barriers to HIV care in rural Saskatchewan.[21,22]

In response to these barriers, our team sought to take a strength-based approach to support Indigenous people living with HIV in Saskatchewan. Grounded by a deep connection

with the land, this study aimed to nurture relationships among our team of researchers, most of whom are Indigenous people living with HIV. We aimed to bring light to the difficulties of those who are furthest away from HIV care in Saskatchewan. In doing so, we sought to better understand the impact of distance to HIV care on HIV outcomes in Saskatchewan.

METHODS – GUIDING PRINCIPLES TO INDIGENISE OUR WORK

Building connections

The foundations of this project were the relationships that we developed and the value placed on living experience. Indigenous people living with HIV, all of whom brought diverse living experiences to this project, passed on their knowledge and collectively held up each other's knowledge. With humility and respect, a group of Indigenous and non-Indigenous researchers who had previously collaborated on HIV research projects in Ontario and British Columbia invited colleagues in Saskatchewan to join our research journey with a focus on HIV in Saskatchewan [Figure 1].[23]

Key principles included: creating a safer space for the work, reciprocal learnings and teachings, connecting with Indigenous ways of healing, valuing the input of all team members equally, using strength-based and accessible language and making significant decisions collaboratively. We welcomed family members into our activities as we honoured the importance of family and sharing knowledge across generations. Team members participated based on their availability (body, heart, mind and spirit), and frequent communication and updates allowed for ongoing participation of team members. We used a co-writing approach where we collaboratively structured and wrote this paper and applied principles of capacity bridging, which 'recognises that everyone around the table has something to share and contribute to the project'.[24]

Culture and Ceremony

Our team came together in Saskatoon on Treaty 6 territory (Treaty 6 encompasses the traditional territories of numerous Indigenous Nations, including Cree, Dene, Nakota, Saulteaux, Ojibwe and homeland of the Métis Nation and Settlers) for a 3-day gathering where Ceremony guided and protected us.[25] Each day started with Ceremony to ground us and start the day in a good way and closed with Ceremony so that our team and our ancestors could rest. Ceremony was how we honoured the first caretakers and walkers of the land we were on. We spent our first day together building connections with the land, eating food and drinking tea from the land, and were gifted knowledge and energy from the land. This knowledge guided us as we discussed HIV care in Saskatchewan and collectively identified our research question. On subsequent days, we continued to connect as we received teachings and made sacred items including medicine pouches and rattles. These teachings were interwoven with teachings about epidemiology and statistics and Ceremony guided us through our work together.



Figure 1: Authorship Circle. In keeping with Indigenous ways of knowing, we present authorship as a circle rather than a hierarchical list. The circle represents our connection with each other through the project and acknowledges each person contributed in a meaningful, unique way. Names are arranged based on the land where they live. The names are arranged around a photograph of the rattles that we made during our gathering.

Indigenising Research Through Eagle Teachings

The Indigenous authors come from many Nations with many teachings. Our many teachings of the Eagle (Xfgaak [Gitksan], Mikisiw [Woodland

Cree], Migzi [Objibwe], Kitpu [Mi'kmaq], Kehew [Plains Cree]) have banded us together [Figure 2].

The Eagle is our link to the Creator and our connection with the Spirit World. The Eagle flies over us to show us we are walking the right path and brings us peace, strength and safety on our journeys. The Eagle teaches us many lessons. It flies the highest of all birds and can fly above a storm and see many miles ahead. It teaches us not to get caught in the storm of conflict and to welcome all perspectives and sharing of wisdom.

The Eagle Feather is held with great Respect and Ceremony. It is a high honour to receive an Eagle Feather. Throughout our journeys on Building More Bridges, our Feathers are with us.

Two-Eyed Seeing

This study is guided by Two-Eyed Seeing and honours the work of Mi'kmaw Elder, Albert Marshall.[26] Two-Eyed seeing is when you can use one eye to see the wisdom provided through Indigenous knowledge and the other eye to see the wisdom provided through settler knowledge systems. This study embodies Two-Eyed seeing and honours the ways of knowing of both Indigenous peoples and settlers and the strong connection between land and knowledge. Expanding on Two-Eyed Seeing, we also strived to achieve Two-Eyed Believing where we valued knowledge from living experience and Two-Eyed Doing where this work aimed to directly benefit Indigenous people living with HIV.[27]

We enacted Two-Eyed Seeing in a way that centres Indigenous knowledge but also invites non-Indigenous knowledge to contribute strength and tools to this work. The relationships among Indigenous and non-Indigenous team members were essential to this work which aims to improve rural HIV care for all. We caution our readers that in other contexts, such as research about or for Indigenous Peoples, Two-Eyed Seeing may not be the best approach and one that is guided by Indigenous self-determination is necessary.



Figure 2: Eagle teachings shared by our Indigenous research team members.

METHODS – QUANTITATIVE ANALYSIS

Analysis methods

The Canadian Observational HIV Cohort (CANOC) is a collaboration of 11 clinical cohorts from across 5 Canadian provinces.[28] Participating sites submitted de-identified demographic and clinical data to the CANOC data coordinating centre. Participants were eligible for inclusion in CANOC if they were aged 18 and over and initiated combination ART (cART) in or after

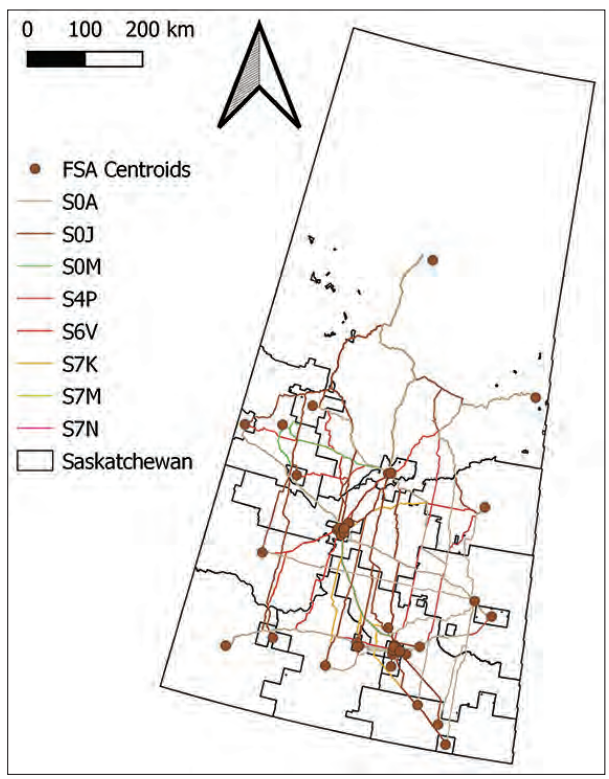


Figure 3: Map of Saskatchewan Forward Sortation Address regions with centroids and shortest driving distance to HIV specialist care locations. This map depicts the Forward Sortation Area boundaries, the centroids within those boundaries and the shortest road distances between centroids.[38,39] Centroids are the geometric centres of the Forward Sortation Area regions.

Table 1: Demographic and clinical characteristics of participants by category of distance to closest human immunodeficiency virus specialist

	Total (*n*=406), *n* (%)	≤25 km to HIV specialist (*n*=295), *n* (%)	≤25 km to visiting HIV specialist (*n*=47), *n* (%)	26-100 km to HIV specialist (including visiting) (*n*=27), *n* (%)	>100 km to closest HIV specialist (including visiting) (*n*=37), *n* (%)	*P*
Distance to HIV care (km)	7 (1-12)	7 (1-9)	1 (1-1)	50 (42-50)	232 (216-232)	<0.001
Distance to CANOC site (km)	11 (7-42)	9 (4-11)	292 (204-631)	50 (42-50)	244 (244-281)	<0.001
Sex						
Male	242 (60)	176 (60)	30 (64)	15 (56)	21 (57)	0.881
Female	164 (40)	119 (40)	17 (36)	12 (44)	16 (43)	
Indigenous						
No	144 (35)	109 (37)	7 (15)	16 (59)	12 (32)	0.001
Yes	232 (57)	162 (55)	37 (79)	11 (41)	22 (59)	
Unknown	30 (7)	24 (8)	3 (6)	0	3 (8)	
Deceased						
No	378 (93)	273 (93)	46 (98)	23 (85)	36 (97)	0.560
Yes	10 (2)	8 (3)	NR	NR	NR	
Missing	18 (4)	14 (5)	NR	NR	NR	
History of IDU*						
No	167 (41)	110 (37)	18 (38)	13 (48)	26 (70)	0.002
Yes	232 (57)	182 (62)	25 (53)	14 (52)	11 (30)	
Unknown	7 (2)	NR	NR	0	0	
Age at ARV initiation (years)	37 (30-44)	37 (30-44)	38 (34-45)	36 (30-46)	39 (34-47)	0.306
Year of ARV initiation	2012 (2010-2014)	2012 (2010-13)	2012 (2011-14)	2013 (2010-13)	2012 (2010-14)	0.454
Baseline VL (copies/mL)	50,454 (13,439-100,010)	44,903 (12,146-100,010)	75,755 (18,076-100,010)	40,950 (6410-97,114)	94,754 (29,124-100,010)	0.071
Baseline CD4 (cells/mm^3)	265 (117-422)	264 (120-426)	245 (113-395)	305 (170-490)	220 (50-326)	0.032
Nadir CD4 (cells/mm^3)	215 (80-337)	215 (81-341)	199 (87-307)	278 (155-404)	117 (50-273)	0.055

*History of injection drug use includes individuals with any reported history (past or ongoing) of injection drug use. HIV: Human immunodeficiency virus, CANOC: Canadian HIV observational cohort, IDU: Injection drug use, ARV: Antiretroviral, VL: Viral load, NR: Not reported due to small cell size

2000 and before 1 January, 2016. This analysis was a retrospective analysis of data limited to the Saskatchewan cohort.

Primary explanatory variable – distance from HIV care

Two distinct variables of distance from HIV care were included in separate analyses (Appendix A). The first variable categorised participants based on the closest available HIV specialist care (within 25 km of an HIV specialist, within 25 km of a community where an HIV specialist visits but where no HIV specialist practices permanently, 26–100 km from the closest HIV specialist, >100 km from the closest HIV specialist). These categories were mutually exclusive as the HIV visiting specialists identified only provided services in communities without a resident HIV specialist. The second was the shortest driving distance between the participants' location of residence and the site where they were enrolled in CANOC and yielded a continuous variable. The two CANOC enrolment sites in Saskatchewan were in Regina and Saskatoon. Distance variables were created using Forward Sortation Area (FSA). Geographic Information Systems (GIS) methods were used to determine the distance from care for each participant based on their FSA [Figure 3]. All GIS analyses were performed using QGIS 3.10.

Table 2: Positive partnership score components and total score by category of distance to closest human immunodeficiency virus specialist

	Total	≤25 km to HIV specialist (*n*=295), *n* (%)	≤25 km to visiting HIV specialist (*n*=47), *n* (%)	26-100 km to HIV specialist (including visiting) (*n*=27), *n* (%)	>100 km to closest HIV specialist (including visiting) (*n*=37), *n* (%)	*P*
Positive partnership score (*n*=305)*	3 (2-4)	4 (3-4)	3 (2-3)	4 (3-5)	3 (2-4)	<0.001
Number of CD4 count tests**						
<3	199 (49)	147 (50)	24 (51)	5 (19)	23 (62)	0.004
≥3	207 (51)	148 (50)	23 (49)	22 (81)	14 (38)	
Number of viral load tests**						
<3	202 (50)	140 (47)	31 (66)	6 (22)	25 (68)	<0.001
≥3	204 (50)	155 (53)	16 (34)	21 (78)	12 (32)	
Baseline CD4						
<200 cells/mm^3	146 (36)	103 (35)	18 (38)	7 (26)	18 (49)	0.270
≥200 cells/mm^3	260 (64)	192 (65)	29 (62)	20 (74)	19 (51)	
Started nonrecommended ART***						
Yes	33 (8)	21 (7)	8 (17)	0	NR	0.043
No	373 (92)	274 (93)	39 (83)	27 (100)	NR	
VL suppressed****						
Yes	126 (31)	95 (32)	8 (17)	14 (52)	9 (24)	0.053
No	179 (44)	125 (42)	28 (60)	12 (44)	14 (38)	
Unknown	101 (25)	75 (25)	11 (23)	NR	14 (38)	

*Reported as median and interquartile range. Possible score range: 0-5, **In the year following ART initiation, ***Based on the contemporary International AIDS Society Guidelines at the time of ART initiation, [30] ****Was suppressed at 6 months (2 consecutive VL <50 at least 30 days apart). HIV: Human immunodeficiency virus, ART: Antiretroviral therapy, VL: Viral load, NR: Not reported due to small cell size

Table 3: Univariate and multivariable linear regression model positive partnership score onto predictors with categorical geographic variables (n=276)

	Unadjusted		Adjusted	
	Estimate (95% CI)	*P*	Estimate (95% CI)	*P*
Distance between home and closest HIV care service				
≤25 km to HIV specialist	Reference	0.001	Reference	0.004
≤25 km to visiting HIV specialist	−0.59 (−1.06-−0.12)		−0.51 (−0.97-−0.06)	
26-100 km to HIV specialist (including visiting)	0.47 (−0.01-0.96)		0.37 (−0.1-0.83)	
>100 km to closest HIV specialist (including visiting)	−0.65 (−1.2-−0.1)		−0.65 (−1.18-−0.12)	
Indigenous				
No	Reference	0.003	Reference	0.002
Yes	−0.44 (−0.73-−0.15)		−0.45 (−0.74-−0.17)	
Year of first ARV initiation	0.04 (−0.02-0.09)	0.200	0.08 (0.02-0.13)	0.005
Number of years living with HIV at baseline	−0.08 (−0.14-−0.02)	0.011	−0.09 (−0.15-−0.03)	0.005
Identifies as heterosexual				
No	Reference	0.003	Reference	0.003
Yes	0.44 (0.15-0.73)		0.43 (0.15-0.7)	

CI: Confidence interval, HIV: Human immunodeficiency virus, ARV: Antiretroviral

Outcomes

The outcome was a composite score which we named the 'Positive Partnership Score (PPS)'. It was a modified version of the Programmatic Compliance Score scoring system which measures how well an individual receives guideline-based HIV care and has been validated to predict mortality.[29] Our team collectively decided to invert the scoring criteria to use a strength-based

Table 4: Univariate and Multivariable linear regression model positive partnership score onto predictors with road distance between home and Canadian Observational human immunodeficiency virus Cohort enrolment site as geographic variables (n=276)

	Unadjusted		Adjusted	
	Estimate (95%CI)	*P*	Estimate (95%CI)	*P*
Distance between home and enrolment site (per 10 km)	−0.02 (−0.03-−0.01)	0.004	−0.01 (−0.02-0)	0.024
Indigenous				
No	Reference	0.003	Reference	0.001
Yes	−0.44 (−0.73-−0.15)		−0.48 (−0.77-−0.2)	
Year of first ARV initiation	0.04 (−0.02-0.09)	0.200	0.07 (0.02-0.13)	0.010
Number of years living with HIV at baseline	−0.08 (−0.14-−0.02)	0.011	−0.09 (−0.15-−0.03)	0.004
Identifies as heterosexual				
No	Reference	0.003	Reference	0.004
Yes	0.44 (0.15-0.73)		0.41 (0.13-0.69)	

CI: Confidence interval, HIV: Human immunodeficiency virus, ARV: Antiretroviral

Table 5: Policy recommendations based on study results

Recommendations	Rationale
Change the practice of displaying an "R" on health cards in Saskatchewan	Many Indigenous people in Saskatchewan experience racism when they try to access health care. The 'R' on health cards automatically identifies individuals as Indigenous without giving them the options to self-identify or not
Increase engagement of pharmacies as HIV care providers and provide the necessary education and support so they can deliver safer HIV care rather than acting as a potential barrier to HIV care	In rural areas, pharmacies may not be familiar with antiretroviral medication and the importance of ensuring a supply without interruption. Increased education and engagement of pharmacies can help to ensure equitable access to antiretroviral medication
Increase peer supports and community-based organisational supports for people living with HIV in rural areas	Peer support is a key component of holistic HIV care. Peer support services are often offered through AIDS Service Organisations which often do not have services in rural communities
Minimise travel burden for people living with HIV. For example, by:	Individuals living with HIV may need to travel outside of their home communities to receive many different aspects of HIV care including physician assessments, peer support, laboratory investigations, medication pick-up and additional holistic services
a. Coordinating appointments for laboratory, physicians and pharmacy into one trip	
b. Working with pharmacies in small communities to ensure uninterrupted ARV supply and safer care environments close to home	
c. Providing early advanced notice of visiting specialist schedules	
d. Providing options for individuals to receive medications by mail	
e. Allowing dispensation of longer duration of medication refills, especially for individuals with stable HIV	
f. Offering shuttles or low-cost transportation options to all health-related services	
Ensure that patients have a choice of several providers (for example, through the creation of an HIV provider directory) so they can receive care from someone they are comfortable with rather than the closest available provider	Some people living with HIV may not feel comfortable with certain providers. In rural areas, there may only be one local provider and if this provider does not have a strong relationship with clients, this can act as a major barrier to care
Support education on trauma-informed care for rural practitioners	Culturally safer, trauma-informed care should be provided universally, including rural communities

HIV: Human immunodeficiency virus, ARV: Antiretroviral, AIDS: Acquired Immune Deficiency Syndrome

approach rather than a deficit-based measurement tool and to acknowledge that HIV care is a partnership amongst people living with HIV and care providers. One element of the score was

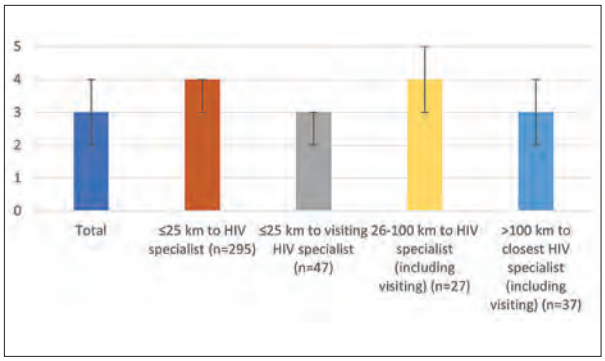


Figure 4: Positive Partnership Score by geographic category. Displays Positive Partnership Score values along with 95% confidence intervals by geographic category.

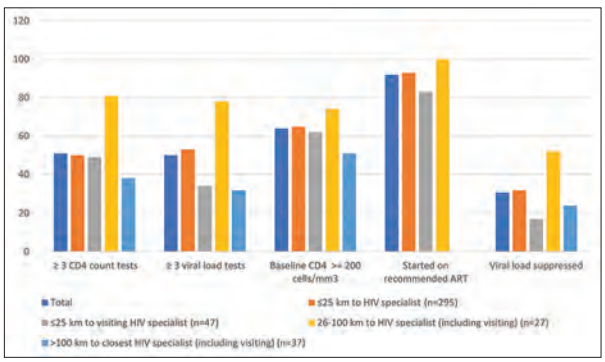


Figure 5: Positive Partnership Score components by geographic category. This graph depicts the proportion of individuals in each geographic category that achieve the care markers included in the Positive Partnership Score. A number of CD4 count and viral load tests are measured in the first year after ART start. Recommended ART is based on the contemporary International AIDS Society Guidelines at the time of ART initiation.[30] Virologic suppression was defined as 2 consecutive viral load measurements of <50 copies/mL measured at least 30 days apart within 6 months of starting ART. Data on starting recommended ART are not presented for one geographic category due to small cell sizes and privacy regulations.

omitted due to the lack of data availability on baseline HIV resistance testing. The PPS included five elements, and a point was given for each element, allowing for score ranges of 0–5 where a higher score indicated better guideline-based HIV care. The elements were: (1) receiving three or more CD4 counts in the 1st year of cART; (2) receiving three or more viral load tests in the 1st year of cART; (3) starting cART with a baseline CD4 count ≥200 cells/mm^3; (4) beginning cART with a guideline-based regimen based on the contemporary International Antiviral Society guidelines at the time of cART initiation[30] and (5) achieving virologic suppression within 6 months of ART initiation.

Statistical methods

Descriptive statistics were performed for all characteristics by distance from HIV care category and reported as frequencies and proportions for categorical variables and medians and interquartile range for continuous variables. Categorical variables were compared using a Chi-squared test or Fisher's exact test. Continuous variables were compared using Kruskal–Wallis test. Statistical analyses were conducted using SAS v9.4 (SAS Institute, North Carolina, USA).

Linear regression models were developed to examine the effect of distance to HIV care on the PPS. A change in estimate method was used to select confounding covariates for inclusion in the final multivariable models. Indigenous identity was self-reported which represents the gold standard for Indigenous identification.[31] Two models were developed using the continuous and categorical geographic variables described above.

RESULTS

A total of 276 individuals were included in the analyses. Characteristics by geographic category are presented in Tables 1 and 2. PPSs were lower among individuals living within 25 km of a visiting HIV specialist (but no permanent specialist) and those living >100 km from any HIV specialist. Figures 4 and 5 present overall PPS and its components by geographic category.

In multivariable regression analysis, distance from care was associated with lower PPSs [Tables 3 and 4]. Living ≤25 km from a visiting HIV specialist (but no permanent specialist) and living >100 km from the closest HIV specialist were both associated with a lower PPS. When examining road distance from a CANOC enrolling site, each 10 km further from the site of CANOC enrolment was associated with a 0.01-point reduction (95% CI-0.02, 0; P = 0.024) in PPS. A distance of 500 km was associated with a 0.5-point reduction in PPS.

The Indigenous people living with HIV on our research team offered several policy recommendations to improve HIV care in Saskatchewan [Table 5]. These included (1) changing the practice of displaying an 'R' on health cards in Saskatchewan; (2) educating and engaging pharmacists in HIV care; (3) increasing peer support; (4) reducing travel burden and (5) ensuring safe and trauma-informed care.

DISCUSSION

Distance from HIV care was independently associated with lower PPSs using two different methods of quantifying distance to care. These findings contribute to the existing body of literature on geographic health disparities and are concordant with prior studies demonstrating associations between distance to care and negative health outcomes.[32-34] There was a linear association between increased distance and lower PPSs which suggests that there is heterogeneity amongst rural areas and that degree of rurality or remoteness is an important factor. Similarly, a linear association has been demonstrated between distance to care and mortality in life-threatening emergencies.[33]

Interestingly, in the categorical analysis, individuals living within 25 km of a visiting HIV specialist also had lower PPSs. This suggests that physician or specialist access alone is not sufficient to optimise HIV-related care and outcomes and that many other factors likely contribute to health inequities. Addressing structural factors such as racism, colonialism and poverty need to complement efforts to improve service delivery to tackle the root causes of health inequity.[35]

In addition to the main findings of these analyses, several other findings are important to highlight gaps in care. The first is that across all groups, the baseline CD4 count was low, which draws attention to the need for increased HIV testing and earlier diagnosis of HIV.[36] The second is that overall, mortality rates were low in this cohort, which suggests that individuals who are linked with care do well. Increased efforts to link and retain individuals in care needs to be a priority for HIV programming and service planning.

The relationship between rurality and health outcomes is complex and multifactorial. Specific to this analysis, important drivers include HIV-related stigma as well as the intersection of HIV-related stigma and racism. Members of our research team have experienced stigma and racism accessing healthcare which is magnified after they have presented their health cards that are labelled with 'R' to indicate they are a 'status Indian'.[37] This affects their ability to receive safe care in emergency departments and pharmacies when they are trying to pick up their ARVs (antiretroviral). In addition to stigma faced by individuals when they pick up their ARVs, interruptions in ARV supply in rural pharmacies can also contribute to treatment interruptions and poorer HIV outcomes.

Strengths

The engagement of Indigenous people living with HIV as research team members was the greatest strength of this study. Ceremony, working with and on the land, and Indigenous leadership enabled this engagement to occur in a meaningful way and the trust and relationships that our team built were critical to this work. Our living experience and understanding of the challenges of receiving HIV care, particularly in rural areas, helped to contextualise the findings and generate recommendations that are relevant within a Saskatchewan context.

Limitations

A significant limitation of this study is the risk for misclassification bias for variables including place of residence which may change over time and history of injection drug use which may not be disclosed due to stigma or mistrust of providers. Furthermore, a dichotomised variable of IDU (injecting drug users) or non-IDU fails to identify those who are in remission. This is an important distinction as it also honours an individual's recovery journey.

Future directions

There is little controversy in the literature that rural populations have poorer health outcomes across a spectrum of health conditions. While additional research in this area will help to document these discrepancies in academic literature and support advocacy for policy change, what is called for is action [Table 5].

CONCLUSIONS

Through a strength-based approach that was grounded in culture, connection, land and Ceremony, we demonstrated how Indigenous people living with HIV can play a key role in HIV research. The results of this study identified the

need for better HIV care in rural areas and found that distance from care can be associated with lower markers of quality HIV care. This highlights the importance of addressing health inequities in rural and remote areas and that Indigenous people living with HIV carry the knowledge needed to develop practical and impactful solutions.

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REFERENCES

1. Pong RW, DesMeules M, Heng D, Lagacé C, Guernsey JR, Kazanjian A, *et al*. Patterns of health services utilization in rural Canada. Chronic Dis Inj Can 2011;31 Suppl 1:1-36.
2. Canadian Population Health Initiative. How Healthy are Rural Canadians? As Assessment of Their Health Status and Health Determinants; 2006. Available from: https://secure.cihi.ca/free_products/rural_canadians_2006_report_e.pdf. [Last accessed on 2021 Oct 30].
3. Ostry AS. The mortality gap between urban and rural Canadians: A gendered analysis. Rural Remote Health 2009;9:1286.
4. Forbes CC, Yu ZM, Cui Y, DeClercq V, Grandy SA, Parker L, *et al*. Rural-urban disparities in total physical activity, body composition, and related health indicators: An Atlantic PATH Study. J Rural Health 2020;36:111-9.
5. Kapral MK, Austin PC, Jeyakumar G, Hall R, Chu A, Khan AM, *et al*. Rural-urban differences in stroke risk factors, incidence, and mortality in people with and without prior stroke. Circ Cardiovasc Qual Outcomes 2019;12:e004973.
6. Smith KB, Humphreys JS, Wilson MG. Addressing the health disadvantage of rural populations: How does epidemiological evidence inform rural health policies and research? Aust J Rural Health 2008;16:56-66.
7. Benchimol EI, Kuenzig ME, Bernstein CN, Nguyen GC, Guttmann A, Jones JL, *et al*. Rural and urban disparities in the care of Canadian patients with inflammatory bowel disease: A population-based study. Clin Epidemiol 2018;10:1613-26.
8. Chan L, Hart LG, Goodman DC. Geographic access to health care for rural Medicare beneficiaries. J Rural Health 2006;22:140-6.
9. Leipert BD, George JA. Determinants of rural women's health: A qualitative study in Southwest Ontario. J Rural Health 2008;24:210-8.
10. Castañeda D. HIV/AIDS-related services for women and the rural community context. AIDS Care 2000;12:549-65.
11. Manis D, Gamble B. Life with HIV in a Canadian Suburban community: A qualitative inquiry of health care and social services access. J Assoc Nurses AIDS Care 2019;30:584-92.
12. Schafer KR, Albrecht H, Dillingham R, Hogg RS, Jaworsky D, Kasper K, *et al*. The continuum of HIV care in rural communities in the United States and Canada: What is known and future research directions. J Acquir Immune Defic Syndr 2017;75:35-44.
13. Gonzalez A, Miller CT, Solomon SE, Bunn JY, Cassidy DG. Size matters: Community size, HIV stigma, & gender differences. AIDS Behav 2009;13:1205-12.
14. Wise JM, Ott C, Azuero A, Lanzi RG, Davies S, Gardner A, *et al*. Barriers to HIV testing: Patient and provider perspectives in the Deep South. AIDS Behav 2019;23:1062-72.
15. Haddad N, Robert A, Weeks A, Popovic N, Siu W, Archibald C. HIV in Canada-surveillance report, 2018. Can Commun Dis Rep 2019;45:304-12.
16. Public Health Agency of Canada. Estimates of HIV Incidence, Prevalence and Canada's Progress on Meeting the 90-90-90 HIV Targets, 2018. Report No.: 200271; 2020. Available from: https://www.canada.ca/content/dam/hc-sc/documents/services/publications/diseases-conditions/summary-estimates-hiv-incidence-prevalence-canadas-progress-90-90-90/national-hiv-estimates-report-2018-en.pdf. [Last accessed on 2021 Oct 30].
17. Montaner JS, Lima VD, Harrigan PR, Lourenço L, Yip B, Nosyk B, *et al*. Expansion of HAART coverage is associated with sustained decreases in HIV/AIDS morbidity, mortality and HIV transmission: The "HIV Treatment as Prevention" experience in a Canadian setting. PLoS One 2014;9:e87872.
18. Robertson M, Laraque F, Mavronicolas H, Braunstein S, Torian L. Linkage and retention in care and the time to HIV viral suppression and viral rebound – New York City. AIDS Care 2015;27:260-7.
19. Focus on Geography Series, 2016 Census; 2017. Available from: https://www12.statcan.gc.ca/census-recensement/2016/as-sa/fogs-spg/Facts-pr-eng.cfm?Lang=eng&GK=PR&GC=47&TOPIC=1. [Last accessed on 2021 Oct 30].
20. Vogel L. HIV in Saskatchewan merits urgent response. CMAJ 2015;187:793-4.
21. Vogel L. Saskatchewan won't declare HIV emergency. CMAJ 2016;188:1071-2.
22. Hall H, Olfert R. State of Rural Canada Report: Saskatchewan; 2015. Available from: https://sorc.crrf.ca/saskatchewan/. [Last accessed on 2021 Oct 30].
23. Benoit AC, Jaworsky D, Price R, Whitebird W, Benson E, Nowgesic E, *et al*. Building Bridges: describing a process for Indigenous engagement in epidemiology. Prog Community Health Partnersh. 2020;14:461-70.
24. Jacco K, Gallard M, Mendell J, Lauscher D, Schmitz D, Stewart M, *et al*. Making allyship work: Allyship perspectives in a community-based research study. J Indigenous HIV Res 2021;11:14-32.
25. Nicholson V, Bratu A, McClean AR, Jawanda S, Aran N, Hillstrom K, *et al*. Indigenizing our research: Indigenous community leadership in HIV epidemiology research. Int J Popul Data Sci. 2021;6:1386.
26. Bartlett C, Marshall M, Marshall A. Two-Eyed seeing and other lessons learned within a co-learning journey of bringing together indigenous and mainstream knowledges and ways of knowing. J Environ Stud Sci 2012;2:331-40.
27. Larcombe L, Hydesmith E, Restall G, Ringaert L, Singer M, Souleymanov R, *et al*. Creating change using Two-Eyed seeing, believing and doing; responding to the journey of northern First Nations people with HIV. J Indigenous HIV Res 2021;11:76-92.
28. Palmer AK, Klein MB, Raboud J, Cooper C, Hosein S, Loutfy M, *et al*. Cohort profile: The Canadian Observational Cohort collaboration. Int J Epidemiol 2011;40:25-32.
29. Kesselring S, Cescon A, Colley G, Osborne C, Zhang W, Raboud JM, *et al*. Quality of initial HIV care in Canada: Extension of a composite programmatic assessment tool for HIV therapy. HIV Med 2017;18:151-60.
30. Previous Guidelines – Adult ARV Guidelines; 2018. Available from: https://www.iasusa.org/guidelines-archive/. [Last accessed on 2021 Sep 09].
31. Smylie J, Firestone M. Back to the basics: Identifying and addressing underlying challenges in achieving high quality and relevant health statistics for indigenous populations in Canada. Stat J IAOS 2015;31:67-87.
32. Chan J, Polo A, Zubizarreta E, Bourque JM, Hanna TP, Gaudet M, *et al*. Access to radiotherapy and its association with cancer outcomes in a high-income country: Addressing the inequity in Canada. Radiother Oncol 2019;141:48-55.
33. Nicholl J, West J, Goodacre S, Turner J. The relationship between distance to hospital and patient mortality in emergencies: An observational study. Emerg Med J 2007;24:665-8.
34. Borren NZ, Conway G, Tan W, Andrews E, Garber JJ, Yajnik V, *et al*. Distance to specialist care and disease outcomes in

inflammatory Bowel disease. Inflamm Bowel Dis 2017;23:1234-9.
35. Nowgesic E. Addressing HIV/AIDS among aboriginal people using a health status, health determinants and health care framework: A literature review and conceptual analysis. Canadi J Aborig Community Based HIV/AIDS Res 2010;3:35-46.
36. Jaworsky D, Monette L, Raboud J, O'Brien-Teengs D, Diong C, Blitz S, *et al*. Comparison of late HIV diagnosis as a marker of care for Aboriginal versus non-Aboriginal people living with HIV in Ontario. Can J Infect Dis Med Microbiol 2012;23:e96-102.
37. Moore H. Saskatchewan Health Card Policy Raises New Questions about Gerald Stanley Jury Selection. Aboriginal Peoples Television Network; 2018. Available from: https://www.aptnnews.ca/national-news/saskatchewan-health-card-policy-raises-new-questions-about-gerald-stanley-jury-selection/. [Last accessed on 2021 Oct 30].
38. Statistics Canada. Forward Sortation Area Boundary File, Census Year 2016; 2016. Available from: https://www150.statcan.gc.ca/n1/en/catalogue/92-179-X. [Last accessed on 2021 Oct 30].
39. Statistics Canada. Road Network File, 2016; 2016. Available from: https://www150.statcan.gc.ca/n1/en/catalogue/92-500-X. [Last accessed on 2021 Oct 30].

Appendix A: Methodology to determine distance to care

CANOC includes Forward Sortation Area (FSA) as geographic data for participants. Although this aggregate spatial data lacks precision in comparison to point data such as a street address, it allows for greater privacy of participants.[38] Geographic Information Systems (GIS) methods were used to determine distance from care for each participant based on their FSA. All GIS analyses were performed using QGIS 3.10. The Statistics Canada Road Network File 2016 and FSA Boundary File 2016 open access GIS shapefiles were used to calculate distances.[38,39] The 2016 versions were selected as they contained the most recent data at the end of the study observation period.

Two methods were used to calculate distance from HIV care. The first method calculated the shortest driving distance between the participants' location of residence and the site where they were enrolled in CANOC and yielded a continuous variable. The second method categorized participants into four prespecified categories based on their shortest driving distance to the closest location where HIV specialist services were available during the study period. The categories, which were defined by members of the research team who are people living with HIV in Saskatchewan included:

a. Living within 25 km of an HIV specialist
b. Living within 25 km of a community where an HIV specialist visits (but not within 25 km of where an HIV specialist primarily practices)
c. Living between 26 and 100 km of the closest HIV specialist or community where an HIV specialist visits
d. Living over 100 km from the closest HIV specialist or community where an HIV specialist visits.

To determine the location of specialist HIV care services, providers in Saskatchewan were contacted by telephone, email, and paper survey to determine their location of practice as well as outreach HIV services provided in other communities in Saskatchewan. The physician directory of the College of Physicians and Surgeons of Saskatchewan was also used to identify Infectious Diseases specialists who had an active, locum or provisional license as of December 31, 2016. Practice locations were classified as primary practice location or outreach practice location based on the setting where they provided most of their services. This process identified primary practice locations for specialist HIV care in Regina (S4P) and Saskatoon (S7K, S7M, S7N) and outreach services in Prince Albert (S6V), Touchwood Agency Tribal Council First Nations (S0A), and Northern Saskatchewan (S0J).

For both methods, the centroid (geometric centre) was calculated for each FSA. Network analysis was performed using the road network file to calculate the shortest driving path from each FSA centroid to the practice locations reported above (seven distinct centroids) or the enrolment sites [Figure 3]. Distances were rounded to the nearest kilometre. For the categorical variable, the shortest distance of the seven was selected as the distance to closest care. The distance to care for the FSAs containing practice locations was set to 1 km (lowest non-zero integer).