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Living in the City

Documenting the Lived
Experiences of the
Island Lake Anishinew People¹

Leah McDonnell
Josie Lavoie
Andy Wood
Derek Kornelsen
Jamie Cidro
Linda Manoakesick

JULY
2018

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ISBN 978-1-77125-411-3

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CANADIAN CENTRE
for POLICY ALTERNATIVES
MANITOBA OFFICE

Unit 205 – 765 Main St.,
Winnipeg, MB R2W 3N5
TEL 204-927-3200 FAX 204-927-3201
EMAIL ccpamb@policyalternatives.ca



Garden Hill First Nation

Garden Hill, Manitoba R0B 0T0
Phone: (204) 456-2085 Fax: (204) 456-9315



About the Authors:

Leah McDonnell works at the University of Manitoba from the Indigenous Institute of Health and Healing: Ongomiizwin — Research.

Josie Lavoie is a Professor with the Department of Community Health Sciences, Faculty of Health Sciences, College of Medicine, University of Manitoba, and Director of Manitoba First Nations Centre for Aboriginal Health Research at the University of Manitoba.

Andy Wood CFNHM, is the Executive Director of Neewin Health Care Inc.

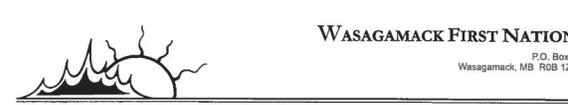
Derek Kornelsen, formerly an Assistant Professor with Ongomiizwin, University of Manitoba started a private consulting business Rootstalk Resources with a focus on working with Indigenous stake-holders and rights-holders, governments, and industry to promote reconciliation and decolonization through the development of various land-based initiatives.

Jamie Cidro is an Assistant Professor in Anthropology at the University of Winnipeg.

Linda Manoakesick has worked with Island Lake First Nations all her life, studies and works with traditional herbs and medicines, and is currently with Island Lake First Nation Family Services.

Funding

We are pleased to acknowledge the generous financial support of: the Social Sciences and Humanities Research Council of Canada through the Manitoba Research Alliance grant: Partnering for Change — Community-based solutions for Aboriginal and inner-city poverty, the SSHRC Partnership Grant titled 'Urban Aboriginal Knowledge Network [UAKN]: Research for a Better Life', with funding for the UAKN grant administered by the Prairie Research Centre of the Urban Aboriginal Knowledge Network, and the Department of Aboriginal and Northern Affairs.



Social Sciences and Humanities
Research Council of Canada

Conseil de recherches en
sciences humaines du Canada



¹ Our study highlights the various challenges community members from what was formerly referred to as Island Lake communities, hereafter referred to as Anishiniiniwuk or Anishininew community members, face when relocating in order to access medical services in Winnipeg and the urgent needs of community members that have currently not been met.

Acknowledgements

The study was conducted in partnership with Indigenous Institute of Health and Healing: Ongomiizwin – Research and Neewin Health Care Inc. The participation of the communities of Garden Hill, St. Theresa Point, Red Sucker Lake, and Wasagamack and Four Arrows Regional Health Authority has been through the mandate given to Neewin Health Care Inc. for primary health care. Overall, 30 community members kindly took part in this study to share their stories. The interviews took place between May and December, 2016. Challenges community members in this study face are urgent and severe. If left unaddressed these challenges will continue to pose severe and negative threats to community members' well-being. The urgency cannot be understated. With sadness and respect, we acknowledge that during this study, four Anishinew community members involved in this study passed away. In respectful accordance with our community partner and Anishinew cultural protocol, our paper wishes to acknowledge the contributions from and passing of: Irene Mason,

Madaline McDougal, Karen Knott-Harper, Rubina Little and Zack Knott.

Our research team also included Cornelius Wood, a well-respected community member from Wasagamack. Cornelius joined our research team to continue to support the needs of his community members, as he had always done, in either his home community, or in Winnipeg. Cornelius was medically relocated to Winnipeg and continued to support Anishinew community members while living in the city. Cornelius provided our team, as he provided his community, with much strength, guidance and advice. It is with respect and sadness we acknowledge his passing in early 2018.

The research team consisted of members from the University of Manitoba from the Indigenous Institute of Health and Healing: Ongomiizwin — Research, community researchers Linda Manoakesick from St. Theresa Point, the late Cornelius Wood from Wasagamack, Zack Flett from Garden Hill, and coordinated by Andy Wood, representing Neewin Health Care Inc.

Abstract

For both First Nations and non-First Nations peoples living in rural and remote areas, accessing diagnostic health services and treatment often requires traveling long distances, and in some cases, relocating to an urban centre for a few weeks or months, or at times permanently. By relocating, patients seek access to life saving, or at least quality of life maintaining, interventions. Although health interventions may be beneficial and necessary to an individual's health, there are several factors surrounding medical relocation that can negatively affect a person's well-being and health status. First Nations peoples' experiences in the healthcare system are different than non-First Nations people, as many experience varying levels of discrimination and racism, policy-related barriers to access services, and inequitable access to treatments. To better understand the realities of First Nations community members experiencing medical relocation, we interviewed 30 First

Nations people from Northern Manitoba who had relocated to Winnipeg for medical reasons, or their caregivers. We heard concerns with patient and caregiver isolation and loneliness; poor access to adequate housing and transportation (in both Winnipeg and the home community); food insecurity; and fatigue when navigating a confusing and, at times, overwhelming, medical system. Those interviewed offered tangible solution-oriented recommendations that include: reassessing Manitoba Income Assistance and the First Nations and Inuit Health Branch (FNIHB) support policy in order to offer adequate and realistic support for patients and caregivers; addressing infrastructural issues and third-party management in home communities; providing a community centre for medically relocated persons and caregivers in newly located area; and providing cultural supports and connections for medically relocated persons and caregivers.

Introduction

“And now I am stuck in the city because of [needing dialysis treatment]. I can’t go home. I wish I could go home, but if I want to live more I have to stay here” *(Participant 1.1).*

For both First Nations and non-First Nations people living in rural and remote areas, accessing diagnostic health services and treatment often requires traveling long distances, and in some cases, relocating to an urban centre for a few weeks or months, or at times permanently. By relocating, patients seek access to life saving, or at least quality of life maintaining, interventions. Although health interventions may be beneficial and necessary to an individual’s health, there are several factors surrounding medical relocation that can negatively affect a person’s well-being and health status. Focusing solely on the specific medical intervention, while failing to consider other realities and concerns that impact a person’s well-being, does not increase overall health status.

This study was developed at the request of, and in partnership with, Neewin Health Care Inc. The participation of the communities of Garden Hill, St. Theresa Point, Red Sucker Lake, and Wasagamack, and the Four Arrows Regional Health Authority has been through the mandate given to Neewin Health Care Inc. for primary health care. The purpose of this study has been to document the lived experience of Anishinew community members from Island Lake when they relocate to Winnipeg to access services. The study was conducted to support the efforts of Neewin Health Care Inc. in advocating for resources to further develop programs meeting the needs of community members who come to Winnipeg for services. The paper is organized in the following manner: background regarding previous concerns and studies conducted in the area, our methodology, findings, discussion, recommendations, and conclusions.

Background

Since time immemorial, First Nations communities on Turtle Island have been practicing with a holistic perspective of health, which includes spiritual, mental, physical and emotional (L. M. Hunter, J. Logan, J. G. Goulet, & S. Barton, 2006; Lavallee & Poole, 2010; Richmond & Ross, 2009, p. 21). Concepts of health are interconnected with social, cultural, and economic determinants that the western health care system can sometimes overlook or not include. However the World Health Organization (WHO) has included in their definition of health acknowledgement of mental, physical and social well-being as integral for one's health and well-being (World Health Organisation & UNICEF, 1978). The western concept of health is largely based on an intervention-specific model that supports the physical well-being of an individual, treating the specific medical ailment or issue to support health and health status. Coming into conflict with an Indigenous perspective of health, western health interventions commonly provide insufficient support for mental, emotional, and spiritual well-being for First Nations communities (Kyoon-Achan G et al., 2018).

The overall health and well-being for First Nations peoples in Canada is deeply rooted in culture and cultural well-being (Adelson, 2005; Bras-

coupé & Catherine Waters BA, 2009; Lavallee & Poole, 2010; Leyland et al., 2016; Reading & Wien, 2009; Richmond & Ross, 2009). A study by Hunter and colleagues further articulated that connection: "Healing holistically starts at any point in life and includes following a cultural path (losing and regaining culture), regains balance (physically, spiritually, emotionally, and mentally), and sharing in the circle of life (respectful interactions with others)" (L.M. Hunter, J. Logan, J.G. Goulet, & S. Barton, 2006, p. 21). The concept of culture involves a variety of different aspects and varies from community to community. Providing spaces to converse in and support traditional language is integral in ensuring cultural safety and continuity (Brascoupé & Waters, 2009).

Supporting Indigenous cultures in urban settings, especially for community members coming from rural and remote settings, is complex. Despite Constitutional recognition of the right to self-government, Canadian Indigenous peoples living or relocating to urban centres lack clear pathways to exercise this right (Lavoie, Browne, et al., 2015). Studies from Lavoie and colleagues have shown that shrinking budgets, fragmented program coverage, and jurisdictional confusion create structural barriers that undermine access

to care and the quality of care accessed by First Nations people. Provider advocacy can help, but also perpetuate perceptions of arbitrariness and distrust. Results also indicated that national policy renewal is required to redress this issue (Lavoie, Kaufert, et al., 2015; Lavoie, Kaufert, Browne, & O’Neil, 2016).

These previous studies focused on First Nations people from First Nations communities in Manitoba, but did not yield solutions that can be implemented at the community-level to mitigate challenges and address needs. Accordingly, the current study focuses on community-level solu-

tions, developed from a community and service provider-based collaborative effort, which can be implemented immediately for effective and meaningful change for the Anishininiwuk, from both Island Lake communities and others. Our study further supports the *United Nations Declaration on the Rights of Indigenous Peoples*, the *Truth and Reconciliation Commission of Canada*, and Manitoba’s Path to Reconciliation Act, and the responsibility of the Federal government to address legacies of colonialism and to work with Indigenous peoples to ensure their health and wellbeing into the future.

Methodology

This study draws on critical theories and Indigenous epistemologies to position and inform the approach to the research. The critical theories drawn upon focus attention on the political and moral concerns arising from the legacy of colonialism, and how these concerns shape the everyday experiences of those who have been marginalized (Battiste, 2000; Gandhi, 1998; LaRocque, 1996; McConaghy, 2000; L. T. Smith, 1999; Young, 2003). Critical theories are also drawn on by Indigenous scholars who emphasize the need to include marginalized voices in studies that aim to address the continued (Alfred & Corntassel, 2005) and aftereffects of colonial (and other forms of) unequal relations (Battiste, 2000; Bourassa, McKay-McNabb, & Hampton, 2004; LaRocque, 1996; A. Smith, 2003). Although the notion of Indigenous ways of knowing encompasses a range of diverse ideas, this body of knowledge converges on the idea that knowledge is underpinned by a world view that reflects interconnectedness, relational values, holistic approaches, and the

pursuit of knowledge about relationships among people, the land, and community.

Indigenous perspectives are particularly critical to the work undertaken in this study given the focus on generating knowledge from the perspectives of people who are directly affected by relocation. The partnership-based approach adopted for this study is grounded in Indigenous ways of knowing and shaped the entirety of the research process. The research approach used a qualitative design grounded in ethnographic methods of in-depth interviewing and the Collaborative Interpretive Processes (CIPs),² with a final thematic analysis conducted on data. Overall, 30 in-depth interviews with Anishinew community members and their families took place; researchers elicited participants' perspectives on the reasons for their relocation, length, and impact on their family and community. Anishinew community members acted as community researchers and were directly involved in the data gathering. The community research-

² CIPs is a process that allows for a greater and more in-depth exploration of already data-rich interviews, which involved bringing the research team together to dialogue on emerging themes. This process granted the research team a more robust analysis of preliminary findings of the data. Themes and ideas discussed during the CIPs are included in the final report as they were part of the analysis that led to the identification of themes and writing style itself.

ers documented participants' experiences and needs during relocation, and elicited participants' recommendations on how needs could be better served. Our team used an iterative process for the creation of interview guides. Community researchers advised and participated in the creation of the interview guides and made recommendations on how to adapt interview questions to relevantly target thematic concerns noted in early interviews. All interviews were digitally recorded and transcribed. Interviews conducted partially and entirely in Anishiniini

were translated into English before transcription. In addition, our team included a representative from the Neewin Health Care Inc. who helped guide and develop the project. Preliminary findings of the project were presented to community by the representative from Neewin Health Care Inc. and feedback was provided, which is incorporated into the writing. Responses from participants and providers regarding recommendations made for improving services and filling gaps for community members are used as the basis for the overall recommendations made in the report.

Findings

It is clear from the previous research and policy review and findings from our current study that at least some of the challenges experienced as a result of medical relocation or other reasons may generate a need to access other services (such as social care, services for children with special needs, end of life care, and educational opportunities) and yield similar challenges. While the participants in this project are Anishinew community members who are relocated for medical reasons, the focus of investigation is on the larger social, economic, and cultural impacts of relocating to Winnipeg rather than their health experiences. The findings are an overview of specific challenges for community members who relocated to Winnipeg, with imbedded discussion that reflects solution-based recommendations made directly from participants.

As research was conducted to understand some of the concerns and barriers community members faced when accessing health services, participants mainly discussed areas of concern or areas that required improvement to better align with their health needs and well-being. Findings from the study are separated into two main categories: (i) factors related to living conditions in home communities; and (ii) factors stemming directly from

relocation (both the act of relocating and concerns that arise once relocated into the city).

Factors Related to Home Living Conditions (Preventative Measures)

Participants noted concerns with poor living conditions in their home communities. Poor living conditions are known to exacerbate previous medical conditions and/or create new medical concerns (Link & Phelan, 1995; Mikkonen & Raphael, 2010; Reading & Wien, 2009; Richmond & Ross, 2009). For many participants, poor living conditions are a reality.

Of major concern is *the limited local access to health services*—specifically dialysis services—in home communities. Although there is a renal health unit in Garden Hill, it was originally designed as an interim treatment centre. The Anishinew communities have created two separate proposals regarding the development of a primary health care facility; one proposal, created in 2008 and based on a smaller proposal written from 2003, was left unfulfilled because of a change in provincial government, while the other is currently under discussion. Currently, the renal unit in Garden Hill is unable to ac-

commodate the number of patients from the Anishinew communities:

“there is no hospital over there, no doctors, no registered nurses over there and we need dialysis nurses over there in the community.

That’s the most important thing we should have it at the community...” (Participant 2.5).

All patients needing dialysis initially relocate to Winnipeg, for a period of 6–8 weeks, for stabilization and education. Some patients, if healthy, relatively self-sufficient, and supported by their family, can return home.³ Options for dialysis include institution-based hemodialysis at the Garden Hill dialysis centre (with the exception of Red Sucker Lake patients), or home-based modalities such as peritoneal dialysis or home hemodialysis. Due to travel restraints, patients from Red Sucker Lake are unable to commute to Garden Hill and must receive treatment in Winnipeg. Waiting lists at the Garden Hill dialysis unit (6 beds only with a capacity of treating 18 patients weekly), and poor housing create sufficient barriers to prevent patients from being able to return home. Patients from Garden Hill who are unable to receive dialysis treatment in home communities, either at the dialysis centre or through home modalities must relocate to larger urban centres, such as Winnipeg, for access to services. Patients from other Anishinew communities must relocate to Winnipeg, or commute three times weekly from either Wasagamack or St. Theresa Point to Garden Hill to dialyze if home modalities are not an option.

Inadequate housing in home communities is problematic for two main reasons. Largely, poor housing conditions create and/or exacerbate medical conditions, causing individuals to

seek medical interventions (many times outside of their home communities). Equally as troublesome, lack of adequate housing can prevent individuals who are receiving non-permanent care outside of their community from returning home.

“What’s holding me to go back home is I don’t have a place to stay... I don’t have a place to stay there, I don’t have a house” (Participant 2.105).

Inadequate access to healthy foods is a contributing factor for poor health.

“That’s why people get sick — there are no proper diets in [participant’s home community]” (Participant 2.5).

Diet makes a substantial impact on overall health and without access to proper foods, individuals can become ill or, as in the case with poor housing, poor nutrition can exacerbate pre-existing health conditions and concerns.

Poor infrastructure is a leading contributor to limited access to clean water and is a major health concern identified by participants. The Renal program in Garden Hill is dependent on the community’s water and sewage system. Frequent disruptions in service interrupt care that patients are receiving. Although ongoing maintenance and a major overhaul, is needed, third-party management of infrastructure and jurisdictional issues with the Federal government often lead to more frequent service disruptions than not.

As a result, poor access to clean water acutely affects an individual’s health status:

“One thing they blame for my skin disease is water. I think it has to do with the chemicals that are in their water treatment plant”

(Participant 2.7).

³ All Anishinew dialysis patients are initially sent to Winnipeg, based on the Renal List created and maintained by the Manitoba Renal Program through Manitoba Health Seniors and Active Living (MHSAL). Once in Winnipeg, the Renal Health programs determines where the patient will receive care. Several factors are taken into account including housing in home community, family, etc. This means that a patient is not guaranteed to receive treatment in Garden Hill even if they are a Garden Hill resident

Poor infrastructure not only contributes to driving people from their homes, but in the case of dialysis, also prevents them from returning.

“...One of the reasons why people don’t ... are not allowed to go back home is they need to have their homes in the community with proper water...”
(Participant 1.101).

Providing access to clean and safe water is a preventative measure for many water-related diseases and benefits the overall health of all Anishinew community members.

In some cases, relocation of various family members who are unable to receive care in home communities can have long-lasting impacts for caretakers, which prevents the caretaker from returning home.

I’ve been living here in Winnipeg for maybe 32 years. I’ve been coming here since I was young in Winnipeg for medical reasons. I cared for my grandparents first and ... my grandfather had a stroke and my grandmother had cancer. And after that, after they passed on, my parents came into the city ..., and I’ve been going through all this for all my life. Taking them to the hospitals and translating, interpreting for them”
(Participant 2.101).

Patients depending on family for support and care can result in generational relocation of families to city centres.

As a result of limited health services locally, coupled with medical conditions that are exacerbated by limited or no access to clean water, healthy and affordable foods, and adequate housing, community members who fall ill are more likely to relocate to Winnipeg for medical treatments. Preventative actions can alleviate some of the burden on the health care system and improve well-being and health status overall. For example, improving access to dialysis services in home communities is a realistic solution that would address a major concern brought up by participants in this study.

Factors Related to Relocation

Concerns identified by the majority of participants when discussing medical relocation to Winnipeg included the lack of transportation, access to housing, food and financial insecurity, and extreme loneliness and isolation. These topics are discussed in detail below.

Once a patient has relocated to Winnipeg for medical treatment, transportation is identified as a contentious issue. Inaccessible and/or unaffordable transportation creates barriers for patients to physically access medical appointments and receive treatments. Participants provided numerous accounts of individuals being unable to afford transportation to and from appointments:

“...people don’t have funds to go where they’re supposed to go, especially medical appointments”
(Participant 2.3).

If an individual patient is unable to support their own needs, it is common for the patient to relocate with a family member who acts as a caregiver; this is not possible in all cases. It should be noted that restrictive social policies also impact a family’s ability to provide care for their loved ones. For example, if a spouse of a patient leaves their job in order to accompany the patient and provide care, the patient is able to apply and access social services, whereas the spouse does not qualify for socially assisted Employment Income.

In the case that a family member can relocate with the patient and act as a caregiver, the caregiver is tasked with transporting their family member/patient to and from appointments, among other things. In one account a caretaker recounts being unable to afford transportation for themselves and their son on multiple occasions:

“... I usually take my son to the hospital with the wheelchair. We walk, going to dialysis three times a week, especially when it’s bad weather and when it’s very cold. Now a days I can’t walk. It’s very hard for me to walk. We’re still going to his dialysis three times a week. Yeah, it’s

hard for us to keep up with the appointments. Sometimes I need fare. It's only a little bit, that sometimes we need help, but nobody comes and helps us" (Participant 2.5).

Lack of access to transportation has negative repercussions on both the caregiver and patient.

The majority of participants identified that securing acceptable housing was highly problematic when relocating to Winnipeg. Although the First Nations and Inuit Health Branch of Health Canada (FNIHB, often referred to as *Medical Services* by participants) covered individuals financially for three months⁴ when first relocating to Winnipeg, the difficulties and barriers involved in finding permanent or long-term adequate housing are vast. Most participants identified lack of support(s) when trying to find accommodations:

"We were covered by Medical Services [FNIHB] ... for three months and we really had a time trying to get a place... We were just trying to help by ourselves, trying to go to doctors or writing letters and we were trying to look for a place to stay, so it took us a while. It took us about a year or two years to get a place, so we really had a tough time for more than two years anyway" (Participant 2.5).

Many who are unable to find housing resort to staying in inexpensive hotels, which are not suitable for their needs. A participant, with a serious skin condition that requires regular access to soak in water, describes their hotel accommodations as:

"...really dirty. Like where I'm staying I can't even take a bath other than taking a shower. I can't even soak myself, those tubs are really

filthy. I really have to clean my skin, that's why I have to be clean all the time" (Participant 2.7).

Participants noted lack of, or unrealistic, financial support:

"They give us funds for [transportation costs to and from dialysis treatments]. Like \$80 for a month, but it costs \$88 to purchase a monthly bus pass..." (Participant 3.1).

The limited financial support generates high-stress situations for individuals, especially those with restricted mobility.

"She said she can't go anywhere, because she's in a wheelchair. She can't pay any fare, like a taxi or a bus. She doesn't have any money. And she can't go anywhere. She just sits here in a hotel..." (Participant 2.102).

It is important to mention that this particular participant lives with a grandchild who is described as "just" old enough to escort the participant to the city for medical appointments, indicating the grandchild is a young person, who may find difficulty in supporting the participant the way that is required of an escort (for example: navigating the city, finding adequate lodging).

The majority of participants commented on the lack of traditional food available to them in Winnipeg, with many relying on family members bringing them country and traditional foods. Although access to healthy foods was not identified as an issue for participants living in Winnipeg, many acknowledged difficulties of affording healthy foods needed to manage their diets, on a restricted budget:

"...they have to have a certain diet that they follow and the welfare doesn't cover that much.

⁴ Under FNIHB policies, an eligible individual who is required to travel repeatedly on a long-term basis has medical expenses (including transportation, food and accommodation) covered for a period of four months (\$ 1.6), after which an assessment is taken place to determine if permanent or long-term relocation is required. If permanent or long-term relocation is required (for example, in the case of dialysis patients), medical expenses for relocation are covered for a period of three months (\$9.10).

They're only allotted so much and you can't buy food on that and... you don't know your places where you can go get stuff like food, like they have food banks over here" (Participant 2.9).

Loneliness and isolation was mentioned by *all participants* in the study. Loneliness and isolation leading to and/or worsening feelings of sadness and other forms of depression are major, immediate and ongoing concerns for community members receiving treatment in Winnipeg. Participants discussed feelings of loneliness being very prominent:

"It's lonely here. I can't do anything"
(Participant 2.6).

There are varied reasons for individuals feeling isolated and lonely. In some cases, one partner has passed away, which leaves the other partner alone and isolated in the city.

"Yeah, that's most hard, the loneliest part. My partner died on [recently] and I'm just here by myself" (Participant 2.6).

In other cases, participants feel cut off from their home communities, families, and other loved ones who are not able to visit when the patient receives treatment.

"It's lonely when you are in a hospital. And I was alone in a room, no visitors, no family visiting so. It's really hard when you are alone and sick. You have to be strong" (Participant 2.4).

Feelings of loneliness and isolation can lead to maladaptive coping practices that have serious implications on a person's health and well-being.

"The loneliest part for people that are here is, sometimes they turn to liquor, sometimes they turn to other things" (Participant 2.106).

Discussion

Our study used the social determinants of First Nations health as a reference point in order to understand social and political impacts on health and well-being. Individuals in the study navigating the current health care system are met with undue amounts of external stresses to their health and well-being, such as finding adequate housing, being able to afford and find healthy and nutritious foods, transportation costs and navigation of the city, and feelings of loneliness and isolation. Andy Wood, Executive Director of Neewin Health Care Inc. and co-investigator on this study provided the following context:

The Anishininiwuk of the Anishinew communities were referred to as “Oji-Cree”, but are not to be mistaken for being “half” Cree nor “half” Ojibway. The Anishinew communities are the only distinct population of their kind in the province. According to community members working in health care services, there has always been a mistaken assumption that one can send an Anishinew community member to a service that is interfaced with Ojibway or Cree service providers. This is not the case, as Anishinew have their own distinct and rich cultural heritage that differs from both

Ojibway and Cree communities. This has left many feeling as though they do not fit in; rather than complain or ask questions, community members try to take advantage of what was there, or being offered, as a means of getting some kind of support. This has added to the feelings of isolation and loneliness and the lack of cultural supports for the Anishinew people.

Preventative Measures

As introduced above, our study generated a range of findings pertaining to home living conditions as well as impacts specific to the experience of relocation. It is important to understand the reported factors stemming from home living conditions as providing key insights into *preventative measures*. These preventative measures may reduce the length of relocation, the impacts specific to relocation, or the need for relocation altogether.

As is evident from interviews, many participants describe feeling trapped and frustrated when in Winnipeg, being unable to leave the city and return home. Identified earlier, in many cases, medical services are just not available in

home communities and participants will be unable to return to their home community unless these services are available. Many participants and their families who relocated relayed a strong and clear wish to return to their home communities. The feeling of uncertainty as to not knowing how long they would be required to remain in the city is another clear sentiment expressed. In order for patients to return, home communities need support to improve living conditions and access to services. Medical and social challenges related to relocation and poor conditions in home communities contribute to making individuals sick and/or exacerbate health problems, which can create a generational (or legacy) of relocation for treatment.

Frequently, when an individual relocates (either permanently or for an extended period of time) to Winnipeg for health services, the impact of the relocation is felt by the entire family. Patients tend to depend on family members for support, which in turn relocates generations of families to the city. While family members may relocate to act as caregivers, there were several circumstances in which a family member who acted as a caregiver passed away, leaving behind children and parents. Although it will not eliminate the need for relocation for certain medical services, supporting communities with access to adequate housing, clean water, and healthy and affordable foods cuts down on the amount and duration of relocations needed and improves the overall health of people in the community.

Removing individuals from their home communities also removes the knowledge that individuals have from their community. Simply placing patients in isolated urban settings, which are not culturally responsive, erodes an individual's cultural connection and will not increase their overall health and well-being. Keeping families together, in a supportive and culturally relevant environment is integral to supporting a person's health and well-being.

A Community-Centred Approach

As outlined in the findings, every participant in the study mentioned feelings of isolation and loneliness being of major concern and impacting health and well-being. The majority of participants in the study requested access to culturally relevant social activities. Many participants advocated for an Anishinew community centre in Winnipeg. Currently, there is no community centre that offers programming and supports specific for Anishinew members. An Anishinew community centre can provide much more than basic services for patients, acting as a centre that supports cultural continuity, socialization, and connection between community members in the city. An Anishinew community centre would service the needs of the Anishinew community and Oji-Cree members from North Western Ontario. Currently, Oji-Cree community members from North Western Ontario are sent to Winnipeg for dialysis needs as well. A centre for patients in Winnipeg would support the health and well-being of Anishinew community members from Manitoba, as well as Oji-Cree from Ontario, by combating depression, anxiety, and stress related to relocation. Participants also mentioned the lack of country foods available to them; a community centre would be an opportune space to facilitate a network that can provide traditional and country foods.

Regarding navigational support, the community centre can act as a hub of knowledge for new arrivals in the city. Many participants found it difficult and confusing when entering the city, unsure where to go to receive supports and services. Furthermore, many First Nations community members who relocate from rural communities to the city for medical reasons have not lived in an urban setting before and do not have a credit history or rental history to provide references for landlords (Lavoie, Forget, Rowe, & al., 2009) (Brandon and Peters, 2015). This is problematic as it creates a barrier for community

members to rent housing without previous references or housing credit histories. Community members who have lived knowledge of navigating in Winnipeg can offer guidance and support for new arrivals. This practice can also establish an urban community in Winnipeg, as opposed to individuals feeling overwhelmed, alone, and forgotten when in the city and/or hospital for treatment. Participants in the study support a local community liaison, living in Winnipeg, to help newcomers to the city orientate themselves and look for housing.

A community centre helps support the youth that have come from communities while they themselves, or a parent/caregiver receive medical treatment in Winnipeg. Guidance and support for youth was mentioned by several patients in the study, with a fear that without supports, youth may face serious issues when living in the city. A community centre can provide a safe, culturally supportive space with access to intergenerational learning from Elders and other community members who frequent the centre.

Development of an Anishinew community centre, in partnership with the Anishinew community, is a culturally safe and responsive approach that participants advocate for. A community centre will address many of the supports

requested by participants, using a cultural wrap-around approach, grounded in Anishinew culture and traditions.

In sum, it is clear that a sustainable solution is to work to reduce the amounts and duration of relocation to whatever extents possible. Clearly, relocation does not only negatively impact the patient, but has negative spin-off effects on the community as a whole. As such, we would expect that augmenting communities' medical infrastructure (i.e. providing dialysis units) would reduce the need for relocation and, therefore, address many of the concerns brought to light by our study.

Where eliminating relocation is impossible, it is clear that preventative measures at home can reduce the need for and the duration of relocation, while community supports within the urban centres are key to ensuring that the negative impacts of relocation on the patient and the patient's family are minimized. Our study demonstrates that community wellness is key to individual wellness. Thus, whether acting preventatively (addressing issues within the home community) or responding to the impacts of relocation itself, it is important to encourage healthy communities both at home and in the urban centre.

Recommendations

The Anishinew communities of Garden Hill, St. Theresa Point, Red Sucker Lake, and Wasagamack, are identified as the only Anishinew communities in Manitoba. While their needs echo those reported in other studies (Lavoie, 2006; Lavoie et al., 2009; Lavoie, Kaufert, et al., 2015; Lavoie et al., 2016), the solutions to meet these needs are specific and different from other First Nations communities in Manitoba and the rest of Canada. These recommendations are made with the needs of Anishinew community members in mind and are based on the analysis and recommendations made by participants in the study. The following recommendations are made:

1. Recommendation for Anishinew Home Communities:

- a) Development of the previously proposed Primary Health Care Centre, located between the communities of St. Theresa Point and Wasagamack, to address health concerns of local community is an essential requirement to alleviate and reduce some need for relocation to Winnipeg to receive medical treatments.

- b) Policy review for third party management of the sewage and water infrastructure is requested as this third party management makes it difficult for the community to address the needs of its own infrastructure and results in time-delays of fixing equipment and service disruptions for all community members.

- c) Improvement of infrastructure related to water and sewage. The current renal unit in Garden Hill is not a stand-alone centre and is dependent on the water and sewage systems in the community. If there is any disruption in services of water and/or sewage, the renal unit is affected.

2. Recommendations for Manitoba Income Assistance Policies

- a) Address issues with Income Assistance policy that will allow caregivers who relocate with the patient, giving up their employment to do so, access to Income Assistance. Allowing caregivers, who have given up employment in order to relocate and care for patients, access to income assistance will reduce financial strain, burden and worry.

b) Reassess the current financial allotment for patients and caregivers using Income Assistance and provide a realistic monetary amount for needs, including but not limited to: transportation, healthy and nutritious foods, and adequate housing.

3. Recommendations for Anishinew Residents Relocating to Winnipeg:

- a) A community centre specifically for Anishinew community members is needed in Winnipeg in order to provide social support and create a space for community members to gather, socialize, provide support for one another, and develop networks and information sharing that can help new patients become familiarized and acclimatized to things in Winnipeg (i.e. where to go to find affordable housing, how to access country foods, etc.), while providing access to transportation to and from the centre.
- b) Transportation support is immediately needed for patients receiving treatment while in Winnipeg (including access to social events/gatherings); transportation

is also needed between the Anishinew communities and Winnipeg city centre.

- c) Liaison/Community worker (preferably someone who speaks Anishinew and English) is immediately needed for Anishinew community members receiving treatment in Winnipeg. A Liaison/Community worker is needed to be present for patients undergoing treatment in Winnipeg. The liaison would be able to help with language barriers, cultural and social support and facilitation for new patients in Winnipeg.
- d) Relevant cultural support (such as access to traditional medicines, translation, and social gatherings) is needed for healthcare, healthcare personnel and other social supports that accurately reflects the language, needs, and experiences of Anishinew community members, including support for youth and other community members that are relocated along with patients to Winnipeg; participants suggested including support for youth in the community centre originally suggested.

Conclusions

This report supports, among other things, the need for policy renewal for First Nations community members exposed to medical relocation. Current policies and their implementation are unable to adequately meet and support the needs of Anishinew community members relocating to urban centres for medical reasons. Measures currently taken regarding medical relocation are unsustainable, band-aid solutions and, in many cases, do not support a healthy life-style for an individual. Policy renewal is required to address serious gaps in service provision and support a better standard of living for individuals receiving care.

In general, First Nations peoples' experience with medical relocation is problematic due to the lack of coordination, jurisdictional understanding, and policy implementation between the federal and provincial governments (and health and social agencies that fall under these levels of government). Anishinew communities are unique to other First Nations communities in Manitoba as they are the only Anishinew communities in the province. While policy renewal is needed to address gaps in service mentioned throughout the report, addressing issues must also address the specific and unique needs

and concerns of Anishinew community members. Inclusion of Anishinew community leadership in discussion of policy gaps and renewal is strongly encouraged, as the community itself understands the serious barriers they face and have already demonstrated resilience in the face of many obstacles. Further, solutions must build on existing strengths and integrate themselves in existing programs and structures. Addressing issues and making changes with the community should be undertaken with the community leadership and also provide a template and space for community engagement and involvement to develop community-led solutions. Future research is needed to discuss further community-led solutions, as well as broader applications of solutions and policy renewal.

Supporting these recommendations will contribute to fulfilling key Federal and Provincial responsibilities under the *United Nations Declaration on the Rights of Indigenous Peoples*, the *Truth and Reconciliation Commission of Canada*, and Manitoba's *Path to Reconciliation Act*, regarding the imperative to address the legacies of colonialism and to work with Indigenous peoples to ensure their health and wellbeing into the future.

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CANADIAN CENTRE
for POLICY ALTERNATIVES
MANITOBA OFFICE

Unit 205 – 765 Main St., Winnipeg, MB R2W 3N5
TEL 204-927-3200 FAX 204-927-3201
EMAIL ccpamb@policyalternatives.ca
WEBSITE www.policyalternatives.ca