

# Understanding Barriers to Implementing and Managing Therapeutic Diets for People Living with Chronic Kidney Disease in Remote Indigenous Communities

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# ABSTRACT

Indigenous peoples in Canada, and globally, experience a disproportionate burden of chronic kidney disease (CKD) and end-stage renal disease (ESRD) ESRD patients in remote Indigenous communities might experience significant challenges in adhering to dietary guidelines. Much research has documented the poor quality, high cost, and limited availability of healthy foods in remote, Indigenous communities. Food quality and availability are poor in remote communities, indicating that persons with ESRD and CKD might have limited ability to adhere to dietary guidelines. This article reports on research designed to understand food-access barriers in remote First Nations for persons living with stage 4 and 5 CKD/ESRD. The study involved semi-structured interviews with 38 patients in remote communities. It concludes with some reflections on the significance of this issue in the context of dietetic practice. *Curr Dev Nutr* 2021;5:nzaa175.

Keywords: food security, Indigenous, northern, chronic kidney disease, end-stage renal disease

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Abbreviations used: CKD, chronic kidney disease; ESRD, end-stage renal disease; TBRHSC, Thunder Bay Regional Health Sciences Centre.

# Introduction

Indigenous peoples in Canada, and globally, experience much higher rates of end-stage renal disease (ESRD) than their non-Indigenous counterparts. In Ontario, 2.9% of First Nations peoples are diagnosed with ESRD compared with only 1.0% of non-Indigenous peoples (1–9). Indigenous people in Canada also have higher death rates due to chronic kidney disease (CKD) and ESRD (10). These patients also have higher prevalence of comorbid conditions such as diabetes and hypertension, further complicating diet and treatment options (1). Racism is an added factor, as both a determinant of health and barrier to treatment, which affects health status and may impact treatment outcomes for Indigenous peoples living with CKD/ESRD in Canada (11–15). Northern and remote location is an added concern: First Nations and Inuit people living in northern, remote communities experience significantly high rates of ESRD than their southern counterparts (4).

Many standard clinical practice guidelines recommend nutrition counseling as a component of ESRD treatment. Medical nutrition therapy with CKD is recommended in both the Kidney Disease Quality Outcomes Initiative (16) and the Academy of Nutrition and Dietetics (17) guidelines. Some research suggests that dietary management can help moderate CKD disease progression through mitigation of anthropometric and biochemical abnormalities (18). There is also evidence that therapeutic diets can decrease the impact of comorbid conditions that are closely linked to diet (such as diabetes, hypertension, and mineralbone disorders) and subsequently improve patient outcomes in CKD and ESRD (16-20).

Some research has identified unique treatment barriers for Indigenous people living with ESRD in remote communities. These barriers include limited community health services and the expense, time, and stress of travelling long distances for treatment, which can impact treatment outcomes (4). Recent research among non-Indigenous adults in the United States documents food insecurity as a precursor to the development of CKD (5, 21-26). Additional research in these populations documents the potential for food-security interventions to prevent the development and progression of CKD (26). There is, however, little to no research that documents the ways in which food insecurity might create barriers to disease management and impact quality of life for those living with CKD and ESRD. Despite the high rates of both food insecurity and CKD/ESRD in remote Indigenous communities, there is also no research documenting challenges to implementing and managing a therapeutic diet for people living with ESRD in those communities. As Schiff and Freill (5) describe, "people living with food insecurity and CKD in any community might experience significant challenges in accessing foods and managing a new diet within the recommended dietary guidelines. In remote communities these challenges become much more complex" (p. 4). These complexities stem from the poor quality of produce and other fresh foods, as well as limited selection of healthy foods sold in local stores in those communities. This means that following therapeutic diet recommendations might be very challenging because the foods included in those recommendations might be very expensive, and as such, inaccessible for those experiencing income-related food insecurity, or those foods may not be available for purchase at all. This article reports on research designed to understand food-access barriers in remote First Nations for persons living with stage 4 and 5 CKD, with stage 5 being considered ESRD.

# Methods

This research was a sub-project of a larger action research project, which included partners from 4 remote (fly-in or winter roads only) First Nations in northern Ontario, the Northern Ontario School of Medicine, Lakehead University Department of Health Sciences, Thunder Bay Regional Health Sciences Centre (TBRHSC), and the Regional Food Distribution Association of Northwestern Ontario. The 4 First Nations in this study had the highest number of CKD/ESRD patients receiving treatment at the TBRHSC, when compared with other remote First Nations in the region.

### Data collection and analysis

Semi-structured, audio-recorded interviews were conducted as part of the larger action research project. For this article, we analyzed questions that focused on patients' perspectives on food access while living on a therapeutic diet in their remote communities. This included questions on participants' concerns with accessing food in general as well as questions regarding the ease of accessing foods that met their therapeutic diet guidelines. Interviews were conducted by researchers during patients' regular visits to the TBRHSC for CKD/ESRD-related health care services. The interviews covered several areas pertaining to the overall project as well as questions related to the sub-project, which is the focus of this article.

To prepare data for analysis, interviews were transcribed and anonymized by members of the research team. The research team for data collection, analysis, and writing included First Nations scholars from northwestern Ontario with experience living in remote First Nations in the region. Three members of the research team who were trained in qualitative data analysis independently reviewed transcripts to identify general themes. These members used conventional content analysis to then collectively develop a preliminary coding scheme to categorize data. One research team member then coded all interview data. Coding followed the initial scheme with a small number of additional codes added as necessary and following discussion among the research team. Once this preliminary stage of coding was complete, and to determine interrater reliability and consistency, a second research team member reviewed half of the coded documents. Only a small number of inconsistencies were identified and resolved through conversation among research team members. Once coding was complete, the research team collectively categorized coded data into general themes and subthemes.

# TABLE 1 Age of participants

Age group (years)	No. of participants		
17 and under	0		
18–29	1		
30–39	4		
40–49	7		
50–59	13		
60–69	5		
70–79	6		
Over 80	0		

# **Ethical considerations**

This research was approved by the Lakehead University Research Ethics Board and the Research Ethics Board at TBRHSC and conducted in compliance with preapproved protocols. Approval for this research was also provided by the relevant approval body for each First Nation (Band Council or Health Director). The specific First Nations that participated in this study are not named in accordance with the research agreements with those communities. Ethics protocols included an informed-consent process, provision of translation services, and compensation/incentive (\$25 gift card) for participation.

# Results

Research participants for this sub-project included 36 persons who were living with stage 4 or 5 CKD/ESRD in the 4 First Nations communities. Four additional persons were invited but declined to participate. The 36 participants represented 90% of persons from these communities who were receiving treatment at the TBRHSC for late renal disease and ESRD. Of the participants, 19 identified as female and 17 as male. **Table 1** presents information on the age of study participants.

Results revealed important information about the challenges of maintaining a therapeutic diet in remote First Nations communities. These challenges were divided into 2 main themes: 1) challenges of transitioning to a therapeutic diet in remote First Nations communities and 2) food security and challenges managing a therapeutic diet in remote First Nations communities.

**Tables 2** and **3** present some quotes that are illustrative of these findings. Each quote is accompanied by a pseudonym, to maintain anonymity of participants, and with a gender identifier (F for female, M for male) and the age of the participant.

# Challenges of maintaining a therapeutic diet in remote First Nations communities

Most participants discussed difficulties in transitioning to and maintaining a therapeutic diet in their remote communities. We identified 2 main themes in participants' descriptions of their experiences with the therapeutic diet: 1) challenges transitioning to a therapeutic diet and 2) food security and challenges managing a therapeutic diet. Within each of these themes we identified subthemes.

Theme 1 (Table 2) was related to challenges transitioning to a therapeutic diet due primarily to insufficient familiarity with and information about the new diet and its recommended foods.

Living with and integrating multiple therapeutic diets	Unfamiliar foods	Insufficient education/Information	
All the things I was told to eat with my diabetes, well, I can't eat those things for my renal diet. With my diabetes, I struggle with trying to control with my renal diet (Cindy, F, 63 y)	I was trying to figure out what the heck it is. It's not normal food that we usually eat. (Carrie, F, 48 y)	They told me I can't eat this or that and then they told me "okay you can eat that now." I just don't know what I can eat now, I don't know. (Lisa, F, 45 y)	
It's kind of difficult for us to change the other foods we used to use you know, like it's difficult to change the food we eat; that transition. (Carrie, F, 48 y)	Just that our people don't know how to get those foods or how to make it. (James, M, 21 y)	You can't see phosphorus in the foods or taste it, so it's really difficult to know what foods are safe to eat. (Carrie, F, 48 y)	

TABLE 2	Key quotes des	cribing the ch	allenges of tra	nsitioning to a t	herapeutic die	et in remote F	irst Nations communities
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We identified 3 subthemes: living with multiple, therapeutic diets; unfamiliar foods; and lack of education/information. The first subtheme was related to a change in diet recommendations after being diagnosed with CKD/ESRD. Patients were quick to outline the challenge in managing renal diet recommendations along with other dietary recommendations for other chronic health conditions such as diabetes or hypertension.

The second and third subthemes (of this first main theme) emerged as new and unexpected results and point to gaps in nutrition education and culturally safe and culturally relevant nutritional counseling for people living with CKD/ESRD in First Nations. Subtheme 3 was related to difficulties transitioning to a therapeutic diet that included unfamiliar foods. Many participants reported they did not want to eat the foods relevant to the therapeutic diet because they did not know what the food items were or did not know how to prepare them. The third subtheme related to the information provided to participants by clinicians. Many participants reported having never been given explicit instructions on what or what not to eat. Others reported experiencing confusion when they were told to eat the foods they were initially instructed not to consume.

The main theme 2 (Table 3) was primarily related to the notorious food-security challenges in isolated remote communities. There were 2 subthemes: 1) availability of appropriate foods and 2) cost. Participants spoke of the challenges related to the cost, quality, consistency, and selection of foods available in local stores. Even for participants not living on low incomes (and who had more ability to afford high northern food prices), the kinds of foods required for therapeutic diets are not available in local retail environments. These anecdotes (Table 3) are consistent with previous research indicating that local

stores can impede healthy food access in northern remote communities (2, 3).

# Discussion

These findings confirm and add new knowledge about food insecurity and living with chronic disease in remote communities. As suggested by some previous research in the United States, food insecurity (due to cost, availability, and quality) can be a significant obstacle to chronic disease self-management (22-26). Previous research in the Canadian north and Alaska also confirms that food-insecurity rates can be very high in remote Indigenous communities (7, 8). Due to these interrelated issues, providing diet recommendations can be a challenge for dietitians who work with patients from northern, remote communities (5). Despite recommended guidelines, dietitians cannot control which foods are available in the stores in their patients' home communities. Even if some of those foods are available, our participants indicated that the selection can be so restricted that meals may feel monotonous and repetitive. Even if patients desire to make dietary changes and embrace the therapeutic diet, they may not be able to do so due to the challenges presented by poor availability, high costs, and poor quality of foods in remote communities (25, 26).

Our findings also add to this existing knowledge, suggesting that dietitians working with patients from northern, remote communities must also reflect upon their tools and messaging. The responses of participants in this study indicate that success with renal diet principles was not limited to patients' food access but was also related to cultural awareness and the education on therapeutic diets provided by clinicians.

 TABLE 3
 Key quotes describing food security and challenges managing a therapeutic diet in remote First Nations communities

 Availability of appropriate foods
 Cost

Availability of appropriate roous	Cost
Well, the thing about the store, there's hardly any things you should eat if you're sick. (Jane, F, 44 y)	If I buy one apple like that \$3.69, one loaf of white bread is \$9. If we bought that good food up there (up north), we would not be able to afford food for the whole month. (Ryan, M, 76 y)
You have to go out of town to get the food you need, pretty much (Charlie, M, 49 y)	It's not the same up north as it is here (Thunder Bay)—If you have \$100 you might be able to get 4 or 5 things. (Mike, M, 62 y)
There's a lack of supply of vegetables at our local store. They tend to run out fast, fruits and vegetables. (Sarah, F, 53 y)	

This research suggests that dietitians located in nonremote communities might provide information to patients in remote communities without in-depth understanding of the nutritional content of marketbased and traditional foods available in those communities, and often without an intimate experience of a northern food environment. Although there is guidance on the incorporation of traditional foods into dietetic practice (27, 28), there is a lack of information on the use of traditional foods in therapeutic diets for ESRD and CKD. For this reason, dietitians providing nutritional counseling for patients living with CKD or ESRD may hesitate to participate in discussions related to traditional food practices. Where traditional foods may not be encouraged, and without knowledge or experience in a northern food environment, it is possible that some of the safest available foods are being discouraged.

These findings also support previous research that suggests that cultural safety in health care must include collaboration and partnerships with Indigenous groups as well as recognition of the broader context of a patient's life (27-29). As such, dietitians cannot rely on food insecurity alone to explain a patient's challenges with the acceptance of a therapeutic renal diet. Through individual self-reflection, we suggest that dietitians need to consider the disconnect between education as provided and the patient's nutritional experience. Whether it be the use of conventional tools created without collaboration with Indigenous peoples, a lack of understanding of northern food environments, or a lack of scientific inquiry into the chemical composition of traditional foods, dietitians must take ownership for their approach. We also suggest a need for dietitians to invest time and research into the development of culturally sensitive resources in addition to improving food access if there is a wish to positively transform dietary experience in ESRD.

As Schiff and Freill (5) suggest, delivering safe foods to patients living in their home communities could allow CKD/ESRD patients to adhere to a recommended diet that is tailored for their condition. Other research by Kolahdooz et al (30) and Mead et al (31) suggested that corresponding educational material relevant to the foods provided may engage patients living with chronic disease in remote communities. These materials could encourage patients and their families to explore new foods and advance their understanding of an appropriate diet for management of chronic disease (5, 31, 32). New food experiences and a wider skill set may diversify future choices, such that individuals requiring a specific diet have greater confidence with the food that is available to them (31, 32). Our results related to the lack of familiarity with foods in the therapeutic diet and insufficient education also reveal a need to create educational resources that are tailored to the unique circumstances and cultures of First Nations patients.

# **Strengths and limitations**

Major strengths of this research included the high level of engagement with the study: 90% of eligible persons participated in this research. We also collected data over a 3-y period, including multiple interviews with each participant, which allowed us to demonstrate the consistency of the findings across time. Another strength is related to the integration of Indigenous people with experience living in remote communities in the data collection, analysis, interpretation, and writing up of findings. There are also several limitations. Most significantly, this study involved only 4 First Nations in a single Canadian province. As such, findings may not be generalizable. Additionally, while our findings revealed concern over the lack of dietitians' familiarity with northern, remote food environments, our interview guide did not include any questions on this topic. Future research could include more specific questions about the type and quality of information received from dietitians.

### Conclusions

This project addresses a key factor related to the management of CKD and ESRD by examining barriers to maintaining a therapeutic diet for Indigenous persons living in remote communities. Our findings may be relevant internationally (such as in the United States and Australia) where other remote Indigenous communities experience similar barriers related to high rates of ESRD as well as high food costs, poor food quality, and lack of culturally safe health care. This is the first study of its kind to target both food insecurity and ESRD in remote Indigenous communities and suggests a need for further research to examine interventions to address the challenges identified in this study.

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