

RELOCATING FROM THE MUSHKEGOWUK TERRITORY FOR HEMODIALYSIS: THE CREE ILLNESS EXPERIENCE AND PERCEIVED QUALITY OF LIFE¹

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ABSTRACT

Remote Aboriginal communities in Canada struggle with the impact of end-stage kidney disease (ESKD). Hemodialysis (HD) is the most common modality for renal replacement therapy, which often necessitates moving to urban centres. This investigation describes the illness experience of Cree from the Mushkegowuk Territory with ESKD who received HD in Kingston, Ontario and, explores the impact of relocation on their perceived quality of life (QoL). A qualitative case study approach obtained the perspectives of 4 Cree HD patients; 3 nephrologists; 3 nephrology nurses; and 3 Weeneebayko Patient Service workers. The complexity of the Cree illness experience regarding HD treatment in an urban centre included: the illness experience of the Cree HD patients consisting of an acute and a chronic phase, di-

1. Acknowledgements: The authors of this article wrote from the perspective of non-Aboriginal individuals who conduct health research with Aboriginal and indigenous Peoples and their communities. In our roles as academics and health care providers, we recognize the necessity to conduct culturally appropriate, sensitive, and responsible research. There are many people in Moose Factory and Kingston, who were cultural consultants — sharing their stories, their cultures, and their traditions and we would like to acknowledge their support and contribution. We would also like to acknowledge the support and contribution of those individuals at Weeneebayko Patient Services. Financial support was provided by the Kidney Foundation of Canada through an Allied Health Scholarship and Queen's University Inter-Professional Patient-Centred Education Direction (QUIPPED). Correspondence can be sent to: Carrie Kolewaski, School of Rehabilitation Therapy, Louise D. Acton Building, 31 George St., Queen's University, Kingston, Ontario, K7L 3N6, Canada. c.kolewaski@queensu.ca

vergence of health beliefs which affected the clinical interactions between patients and healthcare providers, and the social and cultural isolation due to relocating for HD which reduced the perceived QoL of Cree patients. The findings are presented in models co-created with the Cree patients. Satellite renal care programs located in rural and remote Aboriginal communities may significantly improve the QoL of this population as they can adapt to their condition within a familiar cultural context.

Keywords: end-stage kidney disease, hemodialysis, health services accessibility, health beliefs, illness experience, quality of life, Cree, Aboriginal health

INTRODUCTION

Healthcare provision to rural and remote communities of Ontario, Canada, poses logistical challenges involving resource distribution and service coordination. The residents of the Mushkegowuk Territory, who are predominantly Cree, live in Ontario's most northern communities. Local healthcare services exist at the Weeneebayko General Hospital (WGH), the region's primary health care facility. Partnership with Kingston General Hospital (KGH), a tertiary healthcare facility located 1,000 kilometres away in southeastern Ontario, is vital for the delivery of specialized health care.

This paper focuses on end-stage kidney disease (ESKD) within this population. The 16 fold higher prevalence of diabetes in Aboriginal² Canadians (Dyck and Tan, 1994) is associated with ESKD that is twice as common as non-Aboriginal people (Canadian Institute of Health Research [CIHR], 2007; Tonelli et al., 2004). The incidence of ESKD has been reported to be up to 6 times higher in the 45–65 age group (Young et al., 1989). Aboriginal people have a 2 fold higher prevalence of severe chronic kidney disease and a higher mortality rate than non-Aboriginal Canadians (Gao et al., 2007).

In northeastern Ontario, approximately 85% of the ESKD population utilizes hemodialysis (HD) renal replacement therapy. Conversely, when no HD was available in the Mushkegowuk Territory, 80% were on peritoneal dialysis (PD) and only 20% were on HD (Tofflemire and Plourde, 2001). Since HD treatment was not available at WGH prior to 2005, the majority

2. The term Aboriginal in this paper refers to First Nations, Metis, and Inuit People who are recognized under the Canadian Constitution. The term First Nations refers to reserve communities and people who are recognized under the Indian Act. The term indigenous is used in this article to refer to people who have partially or totally retained their traditional languages, lifestyles, and spiritual beliefs that distinguish them from the dominant society and who occupied particular geographical areas before other population groups arrived on the same land. Primary reference is to populations in Canada and Australia.

of individuals living with ESKD and requiring dialysis chose PD in order to remain in their community. At the time of this investigation, permanent relocation to the Kingston community was required for individuals from the Mushkegowuk Territory requiring life-sustaining HD treatment.

The purpose of this investigation was to examine the experiences of self-identified Cree individuals who had relocated to Kingston to receive their HD treatment at KGH. Specifically, this study aimed to answer the question: "What is the illness experience and the perceived quality of life (QoL) and community context of Cree patients with ESKD who required relocation to a distant urban health centre to receive life-sustaining HD therapy?"

METHODOLOGY

THEORETICAL FOUNDATIONS

We write this article from our perspectives as nonindigenous individuals who conduct health research with Aboriginal peoples and their communities. In our roles as academics and as health care providers, we recognize that the divergence of beliefs and health perspectives is a vital, yet often overlooked, component when exploring illness experience and quality of life. Specifically with respect to the Aboriginal population, we recognize the necessity to conduct culturally appropriate and responsible research to identify needs of individuals and communities within the current health-care services and systems within Canada.

This investigation is a controlled cross-cultural comparison. It navigates across personal, ethnic, professional, and political boundaries, as well as medical, social, and geographic contexts. Sensitivity to each of these realms was of the utmost importance to the primary researcher. Vantage is identified by Bonder, Martin, and Miracle (2002, p. 182) as "any observing mind's specific point of view with physical, psychological, and cultural dimensions that restrict how much can be observed at any moment." Eliciting the perspectives of each participant regarding culturally laden terms such as illness and QoL challenged the primary researcher to move beyond her own vantage but also gave insight into the vantages of the participant groups. The theoretical underpinning of this investigation is from the field of cross-cultural communication, specifically from the concepts of cross-cultural analysis from Hofstede (2001) and Trompenaars and Hampden-Turner (1998). The use of the Intercultural Interaction Model (IIM) developed by Proulx (1996) guided the data analysis for this investigation.

STUDY DESIGN

The foundation of this investigation is the interpretive paradigm, specifically the qualitative case study tradition and a single, instrumental, embedded design. A single case study design was chosen due to the impossibility of separating the contemporary phenomena being studied — illness experience and perceived QoL of Cree individuals living with ESKD — from the real-life urban (Kingston) and hospital (KGH) contexts in which they were anchored (Yin, 2002). Nephrologists, nephrology nurses, and Weeneebayko patient services workers involved in patient coordination and support services for the participants were included as subunits of analysis.

PARTICIPANTS

Case study design has an ambiguous sample size as it depends on how the case and the unit of analysis are defined (Creswell, 1998; Patton, 2002). The sample size (n=13) of the current study was obtained by purposeful sampling to ensure comprehensive representation of health support and cultural services utilized by HD patients. The primary participants were Cree patients living with ESKD [(n=4), PT1-4] who had relocated from the Muskegowuk Territory to receive HD treatment at KGH; secondary participants, or units of analysis, included nephrologists [(n=3), DR1-3], nephrology nurses [(n=3), RN1-3], and Weeneebayko Patient Services Workers [(n=3), WPSW]. Demographic information for all participants is listed in Table 1.

Table 1

	<i>Gender</i>	<i>Age</i>	<i>Work Status</i>	<i>Year on Dialysis</i>
Cree HD Patients (n=4)	2 male 2 female	49.1±4.5 yrs (SD)	Previously employed	60.7 ± 9.9 months (SD)
	<i>Gender</i>	<i>Age</i>	<i>Work Status</i>	<i>Year of Work Experience</i>
Nephrologists (n=3)	1 male 2 female	—	All Full time	8.3 ± 16.7 years (SD)
Nephrology Nurses (n=3)	3 female	—	2 Full time 1 Part time	14.6 ± 3.4 years (SD)
Weeneebayko Patient Services Workers (n=3)	3 female	—	All Full time	7±3 years (SD)

The development of standardized ethical policies for research involving Aboriginal Peoples has been difficult (Interagency Secretariat on Research Ethics Policy Statement, 2005); however, approaches to research that build on indigenous knowledge with Aboriginal Peoples have been proposed and

served as guidelines (CIHR, 2007; National Health and Medical Research Council, 2003), as well as community and Cree specific commentary (Louttit, 2006). Ethical approval was obtained from the Queen's University Health Sciences Research Ethics Board. Informed consent in English or Cree was obtained from all participants through translation by a WPSW. Letters of information and consent provided in English were given to healthcare and support providers and were signed by each.

DATA COLLECTION

The primary data collection method was interviews, which were transcribed verbatim. Recruitment of all participants was initiated simultaneously but occurred in two phases. The first phase consisted of the healthcare and support providers volunteering to participate. The second phase involved prolonged rapport building (approximately three months) between the primary researcher and the potential Cree participants, which resulted in four Cree HD patients volunteering to participate in the study once their trust in the primary researcher had been established.

A semistructured approach was employed in all interviews. The interview guide was developed with input from the WPSWs to be culturally sensitive and professionally inclusive. A pilot interview was conducted with a Cree individual who was receiving HD treatment but transitioned to PD prior to the initiation of this study. Completing the pilot resulted in revisions to the anticipated interview structure and process. Interviews with the HD patients took place over a three-month period. An interview guide was utilized only as a reference during interviews with all participants. The interviews with the Cree HD patients did not proceed along traditional lines by completing all questions with one person and then moving onto the next person and interview. Rather, the interviews were organized around the same topic with each of the Cree HD patients until saturation had occurred. The interview process was structured in this fashion to retain topic consistency between interviews and to explore emerging themes of the conversations as the interviews progressed within the group.

Clarification of statements and thematic consultation occurred with all participants, with the Cree HD patients being the most responsive to the member-checking process and the most influential in developing the conceptual models of the study. The consultation process with the Cree HD patients continued after their transfer to the Weeneebayko Dialysis Unit, in Moose Factory, Ontario. The primary researcher made four visits ranging

between 1–3 days in length, in order to consult, review, modify, finalize, and achieve consensus with all of the Cree HD patients to ensure that the conceptualization of their illness experiences in relation to their perceived QoL in Kingston were represented appropriately.

Direct observation, field notes, and analytical journaling were also utilized in this study as part of the data collection process. However, observations and written notes were only employed by the primary researcher as points of reference during the data analysis process.

DATA ANALYSIS

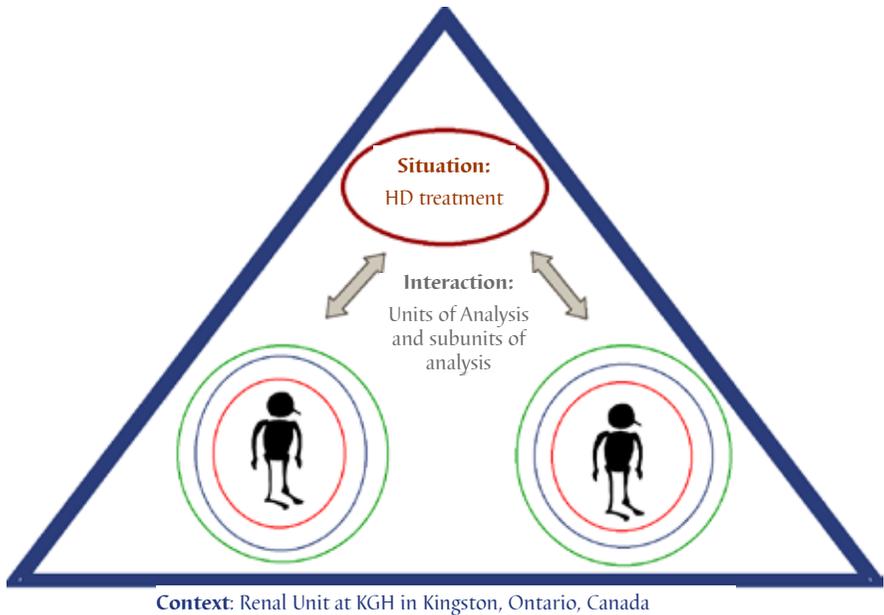
Exploration of the context, the situation, and the identity boundaries of each participant group within this investigation was facilitated by the IIM (Proulx, 1996) (Figure 1). The IIM was used to discover the roles and representations of each participant group and identify the underlying assumptions and cultural orientation that influenced interaction between the participant groups.

Stories told by the HD patients were not fractured into segments during data analysis, but were coded in their entirety to demonstrate respect for and cultural sensitivity to the Aboriginal form of knowledge translation via storytelling. All data were entered into Nvivo7 (QSR International, 2006), a software program utilized for qualitative data management.

TRUSTWORTHINESS

As a strategy of trustworthiness, credibility was fostered in this study by developing the investigator's responsiveness and building rapport with the HD patients, to the point that participants invited the primary investigator into their day-to-day activities outside of dialysis. To broaden cultural awareness and develop culturally appropriate research skills, courses and workshops were completed by the primary investigator. Active engagement with HD patients and WPSWs promoted sensitivity, while discussions with the other investigators promoted reflexivity.

Confirmability was enhanced by member-checking, in which HD patients were keen to participate and observe the emerging themes. Continued updates and engagement with the Cree participants took place during the data analysis, even when they had returned home to receive dialysis at a newly established satellite dialysis unit at WGH. Review, modification, finalization, and acceptance by all the HD patients ensured that the conceptualization of the illness experience was reliable.



Context: Renal Unit at KGH in Kingston, Ontario, Canada



Situation: Required relocation of Cree with ESKD from the Mushkegowuk Territory to Kingston for HD treatment at KGH.



Interaction: Communication and interactions between the HD patients, nephrologists, nephrology nurses, and Weeneebayko Patient Services workers.



Representation: The assumptions held by others known as "representation of self" (examples: male vs. female, adherence to fluid and dietary restrictions vs. noncompliance with treatment).



Role: Inclusion of both attained and ascribed roles (examples: social roles, work roles)



Culture Orientation: Values and beliefs (example: time, individual, collective orientation)

Figure 1: Representation and description of the Intercultural Interaction Model which was modified and utilized in this study's data analysis process (Center for Intercultural Communication, 2005).

RESULTS

ILLNESS EXPERIENCE

The illness experience of the Cree HD patients encompassed two phases: acute and chronic. The acute phase was marked by medical instability necessitating transfer to KGH for treatment and with support services provided by Weeneebayko Patient Services (WPS) to assist with the adjustments to treatment. The chronic phase occurred when Cree HD patients remained in Kingston to access life-sustaining HD treatment and to integrate into the Kingston community after exceeding the 3 month acute phase support provided by WPS. A decrease in perceived QoL was identified in both phases (Figure 2).

Acute Phase: Living in Kingston

Choosing HD treatment

Treatment decision making

While PD was provided within the Mushkegowuk Territory community, the provision of HD required relocation to Kingston. Nephrologists acknowledged that it was difficult to prescribe HD treatment, as they were aware of the life-altering implications of relocation on a patient's life:

If you had a [Cree] PD patient [up North] who's failing, which inevitability they do, you might allow them to become sicker and sicker.... We don't want to switch them to hemodialysis because they have to [be] ... displaced to Kingston. (DR2)

Overall, the Cree patients did not perceive they had a choice of dialysis modality, yet they were aware of making the definitive choice to pursue or decline HD treatment.

Although nephrologists cited health status as the reason for a HD treatment decision, Cree HD patients reported that family influenced their decision to initiate and remain on HD. All of the Cree patients reported consulting with family members, including Elders, spouses, and children. Making an individual choice was regarded as both disrespectful and self-centred:

I didn't want to leave my family. I wanted for us to decide and feel okay for [making the decision]. (PT2).

Patients relocated to Kingston, were effectively isolated in a new community:

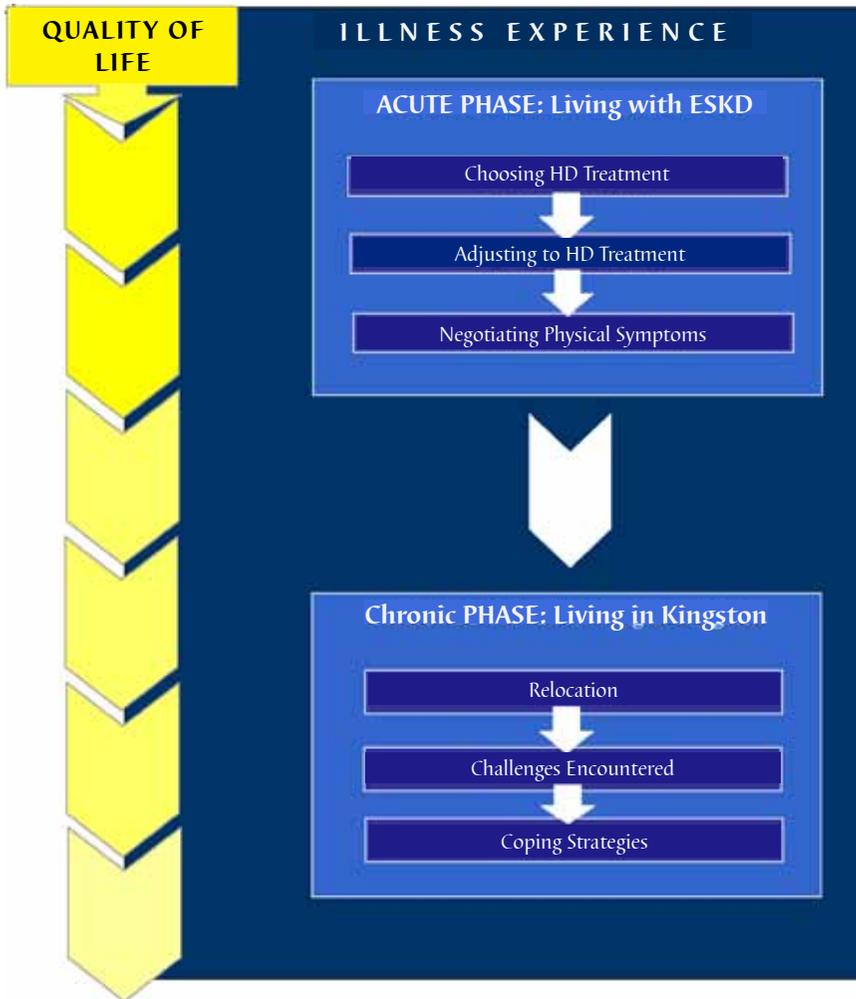


Figure 2: The proposed model of illness experience and perceived QoL of Cree HD patients from the Mushkegowuk Territory living in Kingston, depicting their adjustment to Living with ESKD and Living in Kingston.

I think a lot of them do [HD] for their families.... They are such a tight-knit community, family is so important to them, that [HD] is kind of like a double-edged sword to them. (RN1)

Transfer to Kingston

Despite the negative impact of separating from family, community, and culture, the Cree participants justified their relocation to Kingston for medical reasons:

I know I have to be here to have dialysis. (PT2)

All participants recognized that relocating to Kingston was necessary to access HD treatment:

They're there [at KGH] because they're sick, and they're there because they can't dialyze in their community. (DR3)

They have to literally uproot themselves because this is where they have to go [for dialysis]. (RN1)

Healthcare and service providers acknowledged that the challenges presented by relocation affected the HD patients' health-related outcomes. Offering HD services at KGH was referred to by a nephrologist as a "band-aid solution" (DR1) that failed to provide appropriate access and address the cultural aspects of patient care as a satellite dialysis unit in WGH could:

The physicians, the nurses, the technologists, the dieticians, the social workers, who have all the expertise as far as renal [care] is concerned, they're here. The people with all the expertise as far as Cree culture is concerned are in the Mushkegowuk [region]. (DR1)

Adjusting to HD

Acculturation

HD is a highly regimented medical intervention, from the treatment protocols for healthcare providers to dietary and fluid restrictions for patients to optimize treatment. Cree HD patients' differing health values, beliefs, and orientations were acknowledged by healthcare professionals:

[HD is] a very medicalized, Western technology that, yes, allows them to live, but it also may be a little bit discordant with some of their fundamental beliefs ... I think some of their beliefs and their mentality are different ... they are coming from a different culture. (DR2)

Healthcare professionals commented,

I'm trying to impose my views because I'm hoping they're going to accept my views. (RN3)

We are imposing our views, this is what you need to do to survive. (DR3)

Patients were expected to adhere to their prescribed HD intervention, and were considered noncompliant when their actions showed otherwise.

A Cree HD patient compared the experience of HD to experience at a residential school, correlating the isolation from social supports, removal

from community and culture, adjustment to both urban and medical context, routine of strict HD guidelines, and feeling that there was no alternative for survival (PT3). Many of the patients reported a sense of shame at failing to meet healthcare providers' expectations:

I just scold myself. Drank too much [fluid]. Shouldn't do that ... I got to change it, I got to change it.... (PT3)

Acclimatization

Initiating HD treatment is a foreign and overwhelming process for both Aboriginal and non-Aboriginal individuals. Physical determinants and objective measures such as vascular access and blood work are elements routinely evaluated by nephrologists and the nephrology nurses to assess physiological acclimatization to HD treatment. Healthcare providers in this study also identified a psychological adjustment which was necessary for individuals to grow accustomed to HD treatment. Nurses indicated it was a more difficult process for the Cree HD patients compared to non-Aboriginal patients,

It's hard for them to understand at first ... after 'being on' for awhile, they tend to catch on, but at first I find that they give up. I think they have a harder time. (RN1)

The patients spoke of initially feeling overwhelmed by the technology of the dialysis unit, which evoked feelings of anxiety and fear. They described the process of nurses gaining access for dialysis as "being poked" and reported trauma at seeing their blood circulate through the dialysis machine. Eventually, familiarity of routine and the surrounding environment desensitized the Cree HD patient's experience:

At first it was kind of, it was a sad thing for me, because [HD] was so different, but I'm used to it now. (PT4)

A significant barrier to acclimatization identified by healthcare providers and the Cree HD patients was knowledge translation. Information and educational materials typically provided to individuals newly diagnosed with ESKD or initiating HD were not available in formats other than written English. Each of the Cree HD patients was seriously ill when they initiated HD treatment at KGH, typically travelling by air ambulance directly to KGH, and there was limited opportunity for education sessions or extensive discussions with Cree translators and their healthcare providers.

Although healthcare providers acknowledged that language barriers prevented the transfer of information, patients were nonetheless expected to be responsible for being informed:

There are some Aboriginal patients who want to understand what's going on, ask questions, sort it out, and I think do relatively well. There are many others who don't ask questions, don't seem to understand. (DR1)

The HD patients expressed clearly that a lack of information about their physical status and health outcomes compromised their understanding:

The most confusing thing is that I don't know what's going on with me ... I don't know *anything*. It confuses me. [Am] I going to get better ... I need to know ... exactly what kind of kidney disease or other disease that [give the doctors] the reason for dialysis. What's the prognosis? You know, so I can prepare ... instead of me being in limbo, wondering ... not knowing, not understanding. (PT4)

The patients felt invisible in clinical interactions with healthcare providers:

Nobody talks to me. All of a sudden I'm on [dialysis], given needles. They never explained to me what that's for. (PT4)

The patients perceived that getting healthier, adjusting to their current situation and accepting their condition was delayed due to the lack of clear information provided to them.

Detachment

Detachment from HD treatment was identified as a coping mechanism. A patient recounted that his HD sessions were a “blur,” and it was easier to try and “block out” where he was and what he was doing, to just “get through it” (PT3). Detachment also enhanced the Cree HD patient's self-identification as a patient:

Here, I figure myself as a patient. I'm not home. I'm not doing my everyday things I do at home. I'm not among friends or family. Here I'm just a patient, I really haven't faced it. Being back home, I'm going to realize that I'm a sick person ... that I have renal failure. (PT2)

Conceptualizing themselves as “patients” enabled the Cree HD participants to distance themselves from the life-altering changes of ESKD and HD treatment.

Acceptance

Acceptance was the final phase of the adjustment to HD for the Cree HD patients. It was accepted that HD treatment was life-sustaining and contributed to longevity:

When I first heard “renal failure,” I thought I was going to die in maybe a year. But now I just go on dialysis [and have been] for a year. My blood [gets] cleaned ... [so I can] live day to day. (PT2)

Patients spoke of an inner healing process that would lead to acceptance of their illness and its interventions in order to remain alive:

The acceptance of what’s happening to you ... *is* the healing process. (PT4)

This healing or acceptance process was conceptualized as balancing the three components; the mind, the spirit, and the body, explained thus:

There are three things that you have to respect. There is a mind, a spirit, and a body. In order to survive and accept the way things are, you have to have a balance. If a person is [physically] sick, the spirit is sick and the mind is not good. So in order to heal somebody, you heal the spirit.... (PT4)

Fundamentally, only one aspect of the identified healing triad was being addressed, as HD alters the function of the body. Patients and WPSWs commented that the exclusion of the spirit and the mind slowed the healing process.

Negotiating Physical Symptoms

Communication

Communication was identified by all of the study participants as a frustrating process that negatively affected their interactions. Patients described dissatisfaction with the nephrologists’ perceived lack of knowledge about their physical ailments:

I got fed up with the doctor. He asked me one time, ‘How do you feel?’ I told him, ‘I don’t know, I’m not a doctor. I want *you* to find out what’s wrong with me. I am sick. I don’t know how I feel. Tell me how I feel.’ He said [to] me, ‘I don’t know, I’m not a magician.’ (PT3)

For her part, a nephrologist offered her frustration with the Cree HD patients:

They may be experiencing things that they don't volunteer ... you have to be a detective. (DR3)

The healthcare providers' communications strategies included asking direct questions, speaking slowly, and using translators and nurses to garner information; however, these approaches did not elicit more elaborate responses. Two of the three nephrologists admitted that objective measures, such as routine blood work, were more reliable health indicators than speaking directly to the patients.

Adherence

Nephrologists identified adherence to food and fluid restrictions in their evaluation of a patient's compliance to HD treatment. The compliance of the Cree HD patients was characterized as very problematic. Some healthcare providers sympathized with the patients' struggle:

It is difficult to follow [your diet] at the best of times when you have the support of your family ... you're already compromising in so many ways. It's pretty hard to follow all of the other restrictions we have. (RN2)

Other healthcare providers raised the question of an underlying lack of compliance within Cree HD patients:

I think that there might be a knowledge deficit. I'm not sure if that knowledge deficit is a coping mechanism or if they don't want to be bothered. (RN1)

In the [Cree HD] patients' eyes, [we are] to be there on a daily basis to meet their medical needs and *save* them when they become unwell. (DR2)

The Cree HD patients demonstrated an awareness of these restrictions, but their understanding remained superficial:

Whatever the doctor tells you, you have to do. (PT4)

None of the Cree HD patients were able to consistently maintain the dietary restrictions. Patients indicated they had difficulty in understanding the written English-language materials provided by the dieticians, and in recognizing unfamiliar food items. Patients commented that wild game, such as moose and goose, remained important to them while living in Kingston. Receiving such traditional foods from home created a cultural link to traditional seasonal hunts and social opportunities of gathering for meals.

Impact on daily living

Numerous physical effects were reported by Cree patients due to the extremes of fluid retention and its removal via HD. Prior to their HD treat-

ments, when their bodies were retaining fluid, the Cree HD patients reported feeling as though they were “drowning in [my]self” (PT2). There was an awareness of a systemic overloading of toxins in the body:

the poison damages everything, your liver, your heart, your lungs ... the poison is very deadly ... it damages everything. (PT4)

Fatigue was identified by all patients as the most detrimental physical effect of HD treatment:

You get tired when you get off dialysis; you get that kind of really yucky feeling; you just feel totally drained, and then you'll go lie down, even though you've already been lying on a bed for four hours. (PT2)

HD treatment directly affected the perceptions of health, family life, daily activities, and social roles due to the fatigue and post-HD treatment effects they experienced.

Secondary to the isolation of being away from family, physical discomfort was identified by the Cree patients as a major challenge while in Kingston:

When you think of what we do [by administering HD] in four hours [to the Aboriginal HD patients], what their body would be like the next couple of days, and to just go home, alone, feeling that bad, nauseated. It's just unfathomable to go home to a rented apartment that you can barely afford. It would be so distressing. (RN2)

Chronic Phase: Living in Kingston

Relocation

Rationalizing relocation

As in many rural and remote hospitals in Ontario, WGH is not equipped and is understaffed to provide specialty services, unlike tertiary care centers in urban locations. All participants in the study acknowledged that the HD patients were living in Kingston only because of the renal program and treatment resources at KGH:

In an urban setting, you've got the availability of technical resources, like a hemodialysis machine, and advanced care health professionals, like dialysis nurses with a lot of experience and dialysis physicians with a lot of experience. There's a heavy concentration of those things here [at KGH]. (DR1)

The patients described the access to medical professionals and services while living in Kingston as a “bonus” or “privilege”:

Everything is given to me on a silver platter ... better facilities, better doctors, everything is here. They have a cancer centre; they've got a heart centre; they've got everything here. (PT3)

Healthcare providers acknowledged that the location of renal services and treatment at KGH was not ideal for individuals living with CKD or ESKD in the Mushkegowuk Territory:

I think that it would be best if they could have HD in their own community. Ideally ... it would be nice if they were on home dialysis; failing that ... to have a satellite [dialysis unit] within their region would be second best. The worst, which is what we're presently providing, [is] having them stay in Kingston. (DR1)

Initiation of relocating to Kingston

The process of relocating to Kingston was formidable for the Cree HD patients and required coordination and assistance by healthcare professionals and the WPSWs:

We let Weeneebayko [Health Ahtuskaywin] know that [the HD patient] will have to relocate. They give us the number of months that they are going to fully fund; [HD patients] get 3 months. [WHA] pays for [the HD patient's] room and board while they're looking for an apartment to move into, and then they'll pay for the first and last month's rent when they move into the apartment, and then after that [the HD patient is] on their own. (WPSW1)

“Full-funding” coverage from the WHA via WPS lasted for 3 consecutive months and included accommodation, transportation, and three meals a day while in Kingston, for patients and an accompanying family member. For the Cree HD patients, the realization that they needed to remain in Kingston was distressing:

When you're told you'll be discharged, but you'll be still in Kingston, that's when it hits you. (PT4)

Being a “different kind of patient”

Four categories distinguished the Cree HD patients as a unique subset of both the Cree and HD patient population in Kingston: self-identifying as second-class citizens, designation as Cree First Nations, requiring HD treatment, and perceived abandonment. Figure 3 illustrates the categorical com-

ponents of “being a different kind of patient” as described by all participant groups in this study.

Self-identifying as second-class citizens

Cree HD patients perceived themselves as “second-class” citizens in the general Canadian population. In this study, this perception emerged from the inequitable distribution of medical staff, services and resources in the remote communities of the Mushkegowuk Territory:

How come we don't get that [up North]? How come we don't have that privilege or benefit?... The government doesn't want to put too much money on training dollars [in the North] or professionals [to the North]. I'm scared about the amount of service that I'm provided in [my community]. I feel they are not 100% satisfactory to the standards of other Canadians. My [health resources

Sub-theme: Being a Different Kind of Patient

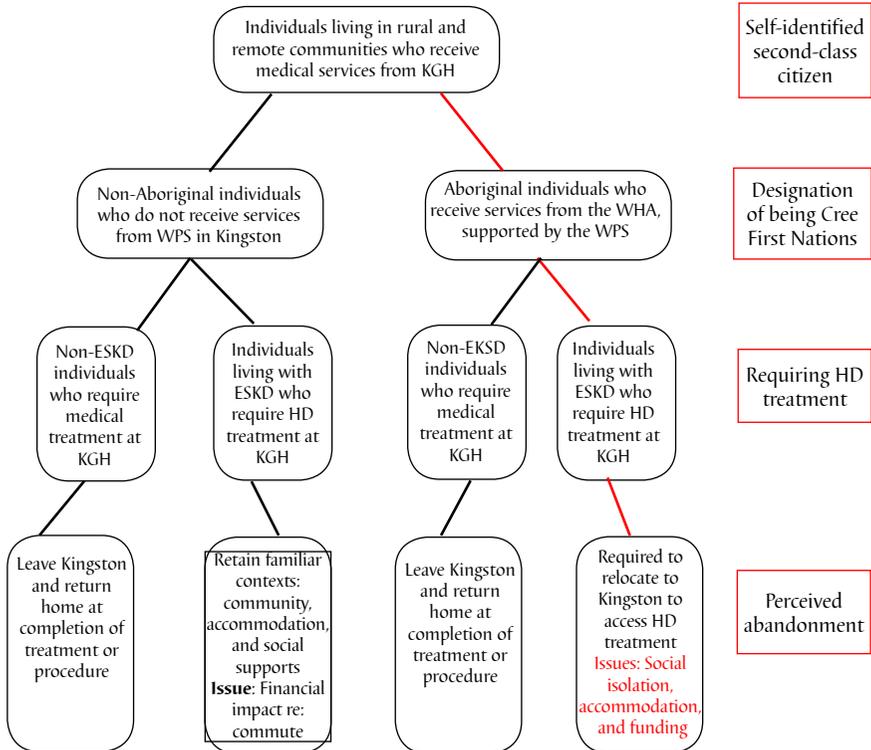


Figure 3: From the theme of *Relocation*, a chart diagram illustrates the four concepts of ‘*Being a Different Kind of Patient*’ which includes: second-class citizen, designation of being Cree First Nations, requiring HD treatment, and perceived abandonment. The red lines represent the experiences of the patients of this study who are Cree and required HD treatment at KGH.

and] standards are very low. I don't think any White man would come [to WGH or the North], they prefer to stay in Kingston for medicine. We [need] to make sure those things — the 'Canadian' standards — are enjoyed [up North] that the Cree have the same thing. (PT4)

Designated as Cree First Nations

Healthcare providers reported that registered Cree HD patients received services that their non-Aboriginal counterparts did not receive:

[At KGH] we have patients that come from Bancroft and we have Caucasian patients who come from [the North]. They have funding issues. They relocate at their own expense, whereas Native patients are covered under the big umbrella of Weeneebayko Patient Services. (RN3)

Three benefits were specifically identified: accommodation, medication, and transportation. Healthcare funding is provided by the federal government via the Department of Indian and Northern Affairs Canada to individuals who are registered by the Government of Canada as Indians within the Indian Registration System. A nephrologist commented that

Healthcare [coverage] of patients who are registered, whether living [in the South or North, is covered federally [and that amount] is greater than for most [non-registered] Ontario patients. (DR1)

Requiring HD treatment

The prolonged necessity of HD treatment differentiated the Cree HD patients from other KGH patients from the North undergoing medical treatment. These patients stayed in Kingston briefly,

... about three days. Sometimes they have to stay if the doctor says or [stay for] another follow-up [appointment], and then they'll go [home]. (WPSW3)

The HD patients were acutely aware of their distinct medical circumstances:

We are the ones that stay longer. The people that have chemo[therapy], they have the opportunity to go back home when they feel better ... it's not like the people that are on dialysis. Some people cannot go anywhere where there's no dialysis; they rely on the dialysis machine to stay alive. (PT4)

Perceived abandonment

The HD patients relied on WPS to provide relocation and transition support into the Kingston community. The WPS administered finances and also assisted in developing social connections to friends, family, and community for the HD patients living in Kingston. Of the four HD participants, one was receiving full funding, and three were no longer receiving full funding

by WPS. Once the Cree HD patients had exceeded their 3 month financial support, they individually drew funds from Canadian Pension Plans and/or Ontario Disability Support Programs to cover rent, meals, transportation, and personal expenses.

The three HD patients who were no longer fully funded expressed a deep sense of abandonment by WPS. The impact of the perceived financial, social, and cultural abandonment by WPS intensified the loneliness and isolation experienced while living in Kingston:

I feel like I was abandoned. Knowing that Weeneebayko Patient Services knows I'm here, even though I'm not funded anymore — it [would] be nice to hear from them saying, 'Hey, how you guys doing?' Once my funding was finished, I felt that the only connection that I had with them was getting my family here and then going home. That was very discouraging for me. (PT2)

The HD patients' transition from full funding to receiving individual monies was exceptionally difficult. As one nurse indicated:

The stresses of trying to manage once they're no longer part of WPS ... they don't have the [same] amount of support. That's really unfortunate because after three months, life doesn't change. They still *need* support. (RN3)

Challenges Encountered

Living in the Kingston community proved to be challenging for the HD patients. Five subthemes emerged as specific challenges they encountered and had to negotiate: culture shock, separation from family, finances, accommodation, and loss of meaningful roles.

Culture shock

Differences between the patients' home communities in the Mushkegowuk Territory and the Kingston community were so profound that the Cree HD patients reported experiencing culture shock:

When you encounter something that you never encountered in your life, something new ... it is a culture shock. You don't know what's going on, and you have to learn by observing, by listening, in the hospital, and outside the hospital, and where you live. (PT4)

Kingston was described as a "big city," "urban," and "White" in contrast to their communities of origin, which the Cree HD patients referred to as "home," "small," "Native" communities. Kingston's urban environment was disturbingly "new" and challenging for the HD patients:

People have to learn how to use the bank; people have to get used to the street signs, be able to follow the city map or town map to go around, get to know how to use the taxi and use the public transit. (PT4)

Kingston was described by all of the patients as inaccessible due to its size, the traffic, and network of streets.

The patients' culture shock was empathetically described by healthcare and service providers, who remarked that patients were "out of their element" in a place that must seem "like an artificial environment" (RN2). Two nurses used the idiom "fish out of water" to describe their perceptions of the HD patients living in Kingston. The difficulty of fitting in was also discussed by a WPSW:

[The HD patients] are lonesome, they miss their homes. They have a hard time getting into the different ways of doing things [in Kingston]. (WPSW3)

Patients described being "uprooted" and "pulled" from their homes and cultural environments. Patients found negotiating Kingston an overwhelming experience and expressed the desire to return home to their social supports and familiar contexts. The contextual factors affecting the HD patients' culture shock was equated with moving from "heaven to hell":

[When] you are from some place just like heaven, you know everything: where everything is, what kind of rocks, what kind of water, what kind of air, the terrain — *everything*. You feel at home because you were born there. When you go to another place, that's when you feel like [you are] in hell.... I want to go home. I don't want to stay here. I don't know how to live here in Kingston. It's a strange world ... different. I could survive on [HD], but I wouldn't last long. (PT4)

The cultural isolation experienced by the Cree HD patients similarly contributed to their culture shock. One nurse highlighted the problem:

Kingston is not really an indigenous centre. I think that is an issue. Since [Kingston is] not a huge community, I think that [the medical community] is not really dealing with the whole picture. (RN2)

A WPSW eloquently identified the disruption in social cohesion as stemming from the loss of a culturally significant sense of community:

Everybody knows everybody [when you] come from a small community. Downtown [Kingston], it's like everybody's a stranger. (WPSW1)

Cultural isolation created by living in Kingston was reported by all participants in the study.

Language barriers intensified the HD patients' culture shock:

If [someone has] never been off the reserve or out of their communities, the first encounter is [with] people ... that speak ... [a] different language, and there's not many people that understand his language [Cree], and he requires a translator. (PT4)

Although WPS provided translation services, these were used primarily for medical circumstances. Low staffing and heavy case-load demands at the WPS often left Cree-speaking individuals to their own devices in the community. The HD patients spoke English with varied fluency and confidence, and mentioned that language barriers magnified the cultural divide and hindered their transition into the Kingston community.

Foreign food and behaviours were also noted by patients as making them feel different:

It [is] surprising when I see people feeding ducks and Canada geese with bread. I laugh at people when I see that happen. To us it's food; to them it's pets. (PT4)

The feelings of being culturally different were prominent in the patients' responses and often stemmed from feeling overwhelmed in an urban context.

Separation from family

Separation from family was identified by all participants as the most difficult thing HD patients had to cope with while in Kingston. Healthcare and service providers unanimously agreed that without their families,

... the [patients'] emotional needs are definitely not being met, and the social support needs aren't being met.... (RN2)

The importance of family in Aboriginal culture was gleaned from patients' comments:

Your whole family is not here. You can't just go out the door and go see them. When you are home, you can go anywhere, but here [in Kingston] you are restricted to being alone. (PT2)

Nobody, I don't have anybody to rely on. (PT4)

I'm only here by myself now. (PT3)

The stress of separation was also reported to have significant psychosocial impact on the Cree HD patients:

There are some patients who have been pretty depressed about their lives, their marriages breaking up because of having spent so much time here without their families. (RN2)

Finances

Although the HD patients expressed gratitude for the initial 3 months of WHA-administered financial support and WPS assistance, they found it difficult to make ends meet:

it is hard to keep money in your pocket for a whole month. I need a little help sometimes. (PT2)

The WPSWs also reported that the Cree HD patients struggled to minimize their expenses:

Everything's so easy to get to up [North], whereas down here it's not, and every time you walk out the door it costs you money. There is *always* a need for money.... The dialysis patients seem to fall short. I think it takes time to sort out the budget. They forget if you buy this, you can't have that. I think that's a little difficult at times. (WPSW1)

Healthcare providers, comparing the HD patients' prior and current standards of living, believed that relocating to Kingston compromised patients financially:

I think they live [here] at the poverty level. It's really a shame. If they were at home, I don't think they would be living at the same kind of level; they'd have a higher standard of living. (RN3)

One patient reported that she received financial assistance from family and her community while living in Kingston:

at the beginning, I got help quite a bit from family and relatives.... Back home, some of the family would help out with [relocating] costs and put canisters out around the community; any businesses, they'll put out a canister. Donated money from the bingo, our band, there's a quite a bit of fundraising. (PT2)

The HD patients reported that demands on their budget in Kingston differed from those at home in the Mushkegowuk Territory, and that the lack of financial resources prevented them from having contact with their families. Phone calls to family, restaurant meals, and entertainment were identified by the patients as additional expenses. The largest monthly expenditure reported by all HD patients was to support their family members:

I didn't want to take any income from my [spouse at home], because that is [for] my family, [for] my household back home. (PT2)

The three HD patients who were no longer funded by the WHA also incurred costs for visitors from home, which included groceries, travel expenses, and utilities.

Accommodation

As long as the HD patients were fully funded, they stayed at the WPS-operated Geaganano Residence, known as "the Lodge." Geaganano Residence ("our home" in Cree) provides short-term accommodation for any Cree individual and their family from the Mushkegowuk Territory when they come to Kingston for medical appointments. Each of the HD patients cherished their time at Geaganano Residence because of the cultural connection and social environment:

I feel more at home, I see other Native people around. (PT4)

Geaganano Residence was seen by healthcare and service providers as facilitating the patients' relocation to Kingston:

They stay at the Lodge for a period of time. I think that there is a lot of shared experiences they have amongst each other, something that they may all relate to. (RN2)

Geaganano Residence is not a large facility, nor does it offer long-term accommodation, so Kingston hotels, motels, and apartments are utilized by WPS as accommodation alternatives. Finding an apartment in Kingston was challenging for both the HD patients and the WPSWs who assisted in the search:

I started looking for an apartment in June. I asked around, checked the newspaper. Three apartments to look at ... I was supposed to look at one of the apartments. I called [and they said], 'Oh, the apartment for you has been taken.' Okay ... I went to check the next one: three floors no elevator there. That one, no good. This one [that I live in], it costs me \$640 a month: two bedrooms, too expensive. (PT1)

They told me to look for an apartment, and I couldn't find one. Everybody wanted a year lease. I couldn't do it. I couldn't climb the stairs. So I stay at the Super 8 [motel]. (PT3)

At the time of the interviews, two HD patients had their own apartments, one was living in a motel to accommodate limited mobility, and one was

staying at Geaganano Residence. The three HD patients with their own accommodation noted that they missed staying at Geaganano Residence, but preferred their independent living arrangements because they could host family members and friends for extended periods of time.

The Cree HD patients reported feeling both anxious and empty when they left the Geaganano Residence to live in apartments or hotel rooms:

Here you're restricted to being alone ... being here this long, it is lonely at times. I wouldn't dare live by myself. Oh! I did that once. I would swear I was going to have an anxiety attack, just the fear of nobody around. (PT2)

Depression was identified as a consequence only by the healthcare providers, particularly the nurses who frequently interacted with the HD patients:

At one point, he said to me how depressed he was and how upset, how he hadn't seen his wife, in what seemed like weeks, when she'd only been gone for a few days.... To him, it seemed like forever.... How can you compensate for being depressed because your kids aren't there, or your wife and you can't be with her? I don't think we can. I don't know how we can. (RN2).

A nephrologist commented that depression was not specific to Cree HD patients but common for all HD patients:

[I] think [patients] are all failed [by the medical system] in that regard. For all of them I think depression, in particular, is really underdiagnosed. (DR3)

Healthcare providers acknowledged that the involvement of family members is an asset when living with a chronic illness, and recognized that the lack of social contacts for the Cree HD patients affected their health outcomes:

It's truly hard for anybody to do it by themselves. A lot of us require or lean on our families for encouragement. When the spouse or the loved ones are at the patient's bedside, it's great to be able to teach them because they reinforce ... the information that you give [the patient]. (RN2)

Loss of meaningful roles

Patients relied on their HD therapy both for their physical existence and also for consistent activity in their weekly routines. They regretted the loss of meaningful personal and professional roles that were forfeited because of relocation, and described a sense of pride and accomplishment in the positions they held in their communities:

I never went to high school; I never went to college or university; I only went to grade [school]. I never went any place, but I've been able to [hold an administration position in city name], to become [an executive] in a corporation. I was able to do that. (PT4)

In Kingston, the thrice weekly HD treatment substituted for the patients' valued roles and activities in the North:

We don't do anything. Just come here, Tuesdays, Thursdays, and Saturdays and do our dialysis.... At the end of the day, I look forward to my next dialysis. That's the only way to get through here. That is what I think about. (PT3)

Nurses echoed the significance of HD treatment in the patients' lives and questioned the quality of life afforded them in Kingston:

They're here for dialysis; there's nothing else. You get the feeling that there's nothing here except dialysis. They're here in a rented apartment, and it's a city where their family isn't. They come for these treatments; that's all really they have to do. They're kind of put in an odd situation, and they sit around by themselves and wait for the next treatment. You get the feeling that it's not a really great life. (RN2)

One nurse articulated the question she felt all the HD patients in this study were asking themselves:

Why am I living, if I'm only living to dialyze? (RN3)

Coping strategies

Return visits home

The HD patients spoke fondly of returning home where they could reconnect with their family, friends, and community. HD patients' visits home to alleviate homesickness were few and far between, and placed their physical health at risk by missing scheduled dialysis sessions. Healthcare and service providers described some patients' homesickness at a "crisis" level.

Regardless of the patient's funding status, the WHA funded three visits home per patient per year. The trip required coordinating the HD patients' requested dates to travel, alternate HD sessions within the dialysis schedule, and the availability of seats on the WPS-organized charter flights. WPSWs were sympathetic about the complex travel arrangements:

They call me and say; "Well, I want to go home." So I call the nurse and make sure this is all right; then I call WGH [to coordinate if there is seat availability on a flight] and say, "so-and-so wants to go home this day," so we put their

names down. We *try* not to overbook, so that person can go home — but it doesn't always work. (WPSW1)

Patients reported that their requests to travel home were promptly acknowledged by WPS, but the actual traveling was routinely delayed for weeks or even months. Due to the delay, many HD patients missed social and cultural events, such as funerals, memorials, graduations, or other significant community events, such as hunts. Trying to coordinate flights home was acknowledged as a frustrating experience for all involved.

Ensuing physical hardships, such as the build-up of fluid, negatively affected the patient's physical well-being, as well as the efficacy of the next HD treatment:

They've had an extra day off of dialysis, and most of them can't tolerate that. Often we get them back by [emergency] air ambulance [earlier than their planned return to Kingston]. (RN2)

Despite travel difficulties, the patients unanimously found the visits to be worthwhile:

Oh, you wouldn't believe the hugs I got. You wouldn't believe the people telling me, 'Good to see you.' ... I went to the store, and I think practically everybody that I met at the doorway was surprised to see me. It made me feel so happy to know that there's people that care. You don't see that till you get sick and [have to] leave the community to go get your health back. (PT2)

The pleasure of seeing friends, family, and community caused significant emotional distress for the patients, who had to return to Kingston for treatment:

I was excited going back [home], and I was heartbroken when I came back [to Kingston]. It was hard. I needed to come back [for HD]. I want to still live a bit longer on earth for my grandchildren, my wife, and my daughters. (PT4)

Visitors coming to Kingston

Having friends and family come to Kingston to visit removed the health risk posed by patients flying home but caused financial hardship:

Since I'm not funded anymore, [my family] come on their own, but they're allowed to get on the charter. (PT2)

Poor weather, travel distance, and coordination with school or work hindered the duration and frequency that visitors could come to or remain in Kingston. As one patient commented about her husband's visits:

He came here without pay. He almost didn't get the time off to come see me because he still owes some hours from previous stays. He came and had to stay an extra two weeks because they kept bumping him from the flights. He owes them two weeks ... he had to get back to work. (PT2)

The female and male HD patients responded differently to their visitors; female patients reported needing to have their family with them and received more frequent visits of a longer duration than male patients. The male patients reported phoning home as their main method to communicate with family members and did not report the same frequency or need for family to visit. Both male patients reported saving money by not having family visit them in Kingston:

I [try to] have a little bit left over ... I saved 100 bucks for my grandson's birthday. (PT3)

Kingston support network

Weeneebayko Patient Services was reported by all participants as a vital social and cultural patient resource, and was commended by healthcare providers for coordinating and supporting the medical care of Cree individuals from the Mushkegowuk Territory. WPSWs reported that,

They feel at ease with us. I think it's mainly because of the language. They know that we would understand because we're Cree, we would think the same way and feel the same way about things, and I think that's why they feel comfortable with us. (WPSW2)

For the HD patients, WPS and its Geaganano Residence was reported to provide "... a sense of community ..." (PT4) and offered a cultural connection:

The main thing is the healing. It is pretty hard; it's hard because the personal support, like family support, isn't there. They're so far away from home. I know we try the best we can to be their family. (WPSW2)

Another important source of support was the patients' peer group. All of the Cree HD patients dialyzed in the same dialysis unit, on the same evening schedule. The common experience of having HD treatment together and coping with similar challenges of living in Kingston formed a bond between the patients:

I see a lot of laughter and talking with their families, talking amongst themselves a lot. There's a lot of inside jokes. There's definitely community. They're away from home, and they talk and joke amongst [themselves]. [Patients] bring

their family and their kids in [to visit the others]. They kind of have their own little [community]. (RN2)

Perceived quality of life

The nephrologists indicated that quality of life was to them a broad, abstract concept:

I would say that your sense of well-being physically, well-being emotionally, and your sense of well-being in terms of your relationships with the important people in your life — that, to me, is quality of life. (DR2)

Nurses spoke of QoL as having a spiritual impact:

There's a holistic part to quality of life, where all your needs are met — physically, emotionally, spiritually, psychosocially. (RN3)

Healthcare providers also referred to control as stemming from life choices:

[Quality of life is] being able to wake up in the morning and feel like you can control your day and do what you want to do without parameters; feel like you have some control and are happy, are doing what you've chosen to do; being able to make plans, dream, and work hard.... (RN2)

Weeneebayko Patient Services workers saw QoL as “the way you live” (WPSW1), but necessarily free from illness:

When you're sick your quality of life is not very good. (WPSW1)

Unique to the WPSWs' description of QoL was adjustment, a “healing process” that patients must transition through in the presence of illness:

... accept[ing] your illness and deal[ing] with it the best way you know how, and to also seek help both emotionally and physically. (WPSW2)

HD patients found the term “QoL” formal, and, like the WPSWs, preferred the term well-being. Spirituality was a core concept in the HD patients' description of QoL, featuring a holistic orientation, inner spirit, and a balanced life:

my spirituality and my well-being, my outlook ... my medication, my health ... me in medical terms, me in spirituality terms ... all connecting in one big circle ... joining [all] this together [is] creating quality of life. (PT2)

Another patient acknowledged the significance of family and community in describing QoL:

Well-being is the situation of one individual. Quality of life has many circles so it's all different. Quality of life has many circles, billions of them ... quality of life is not *one* thing, it's the circles of it. (PT4)

An individual's perceived well-being is linked to the circles of family and community. Two concepts emerged from the HD patients' discussion of QoL that highlights the holistic orientation of Aboriginal health beliefs: respect and the mind-body-spirit connection.

Respect

The concept of respect includes both self-respect and respect for others:

Quality of life is in yourself, inside of you. It's [your] self-respect ... you respect others, but you've got to respect yourself. (PT3)

The concept of respect was strongly linked to the traditional spirit-oriented beliefs of the patients:

If [there is] no respect, then quality of life of that person diminishes.... An individual could offend the spirit world because [of the] lack of understanding and of respect to the spiritual things on earth. The nature that was created has a spiritual life and death. The water, the trees, the animals, the sky, the fishes in the water — the reason that they are alive is because they have spirits in them. The quality of that person's life could snowball to the other circle, from one generation to the next. The next generation could be punished for what that one individual has done to offend the spirits. (PT4)

One HD patient declined to define QoL because she did not want to offend the spirits; instead, she reserved her comments in order to “wait to see what will happen” (PT1).

Mind-body-spirit connection

The second concept of QoL identified by the patients was the mind-body-spirit connection. A description that highlights interconnectedness between the mind-body-spirit and well-being was provided by one patient:

The mind, the body, and the spirit, they have to function together.... The reason that you are here is those three things. If there's no spirit in your body, you're dead. If there's no mind, the spirit is there, the body is there but not functioning the way it's supposed to function. We have a body. We need those things to function. When the body is gone, the mind is gone, but the spirit lives on. That's

the only purpose that the person is alive, because of the spirit. Everything on earth is a spirit; the rocks, the trees, the water, the air have spirit. (PT4)

Correlating illness experience and quality of life

The interdependence of the illness experience and QoL became apparent through participant discussions. One nurse indicated that

the quality of life for patients with a chronic disease like kidney disease is very closely related to their illness experience. (RN1)

More specifically,

Illness impacts on quality of life, and I think that the illness experience of our Aboriginal patients is significantly worse. (RN2)

Impact of ESKD and HD treatment on quality of life

The impact of ESKD and HD treatment refers to the physical hardships imposed by ESKD and HD. The QoL of HD patients was reported to diminish over time in a “graded fashion because many of them are still alive, but that’s the very least” (DR1).

WPSWs echoed the opinion that HD treatment impeded the day-to-day life of those who require it to survive:

When you’re sick, your quality of life isn’t very good.... It would be an awful way to have to live, being hooked up to a [dialysis] machine just about every day. [HD] is something you can’t do anything about, it is restricting. (WPSW1)

The patients emphasized that HD treatment was a necessity to live and discussed the significant influence of HD treatment on their overall QoL:

When you’re sick, you’re not normal: you’re probably 80% or 50%, 30% of [your] normal [state]. You cannot be 100% because there are times that your body starts to deteriorate ... if there was no dialysis machine you know my health will be zero – dead and gone. (PT4)

Impact of relocating to Kingston on quality of life

The Cree HD patients’ difficulties in adapting to an unfamiliar city, culture, and context to receive treatment is expressed in the impact of relocating to Kingston:

Within the dialysis population, I would say it is the displacement that would make me perceive that their quality of life is less than the other patients. (DR2)

Healthcare providers noted that the HD patients in this study experienced profound loneliness and isolation affecting their QoL because of the med-

ical need to receive HD treatment in Kingston rather than in their own communities. In particular, isolation from social supports was perceived to affect QoL:

The quality of life of [the HD] patients that are living in Kingston is pretty poor because they don't have the social interactions or the positive social network. (DR1)

When exploring the patient's point of view regarding their QoL in Kingston, one patient reported

I think [of my life as] divided up in half. Half is life here [in Kingston] and the other half is on pause [at home] when I left. (PT2)

A strong dissatisfaction with remaining in Kingston was expressed:

I'm miserable here. (PT1)

I can't describe the words to the way I feel here, [other than] it sucks. (PT3)

Residing outside of their familiar environment and away from their social and cultural connections diminished the HD patients' perceptions of QoL.

HD patients' conceptualization of illness experience: Tree analogy

A unique component to this research was the co-creation of a diagram by Cree HD patients and the primary author to depict this study's findings. Over the course of this study, it became apparent that the orientation and representation of illness experience and the perceived QoL was interpreted differently by the researcher and the HD patients, consisting of the progression of illness (Figure 4) and the illness experience and perceived QoL (Figure 5).

The HD patients created a tree analogy to depict their illness experience while living in Kingston. In the analogy, the tree was chosen to represent a Cree individual. A tree starts as a small seedling within a forest of trees, protected by the other trees that surround it as it grows. From season to season, the tree matures with each passing year. Forces of nature such as flood, snow, and drought affect the tree's growth. Each passing season, the tree grows taller and the trunk grows wider. The story of the tree's life is recorded; the rings within the tree's trunk indicate experiences from season to season. The patients spoke of their experiences of being diagnosed with ESKD and of relocating to Kingston as being shown within the rings of their trees, with the outermost ring being their current experiences in Kingston (Figure 4).

The tree was chosen by the patients to represent a Cree individual because trees can be transplanted from their place of origin to another loca-

tion. The patients equated being relocated to Kingston with being uprooted from their communities and transplanted into the Kingston community. They described how they continued to grow after transplanting, indicating their process of adjustment to the Kingston context. The themes discussed under “living with ESKD” and “living in Kingston” were represented by the branches of the tree. Essentially, the patients stated that they could survive

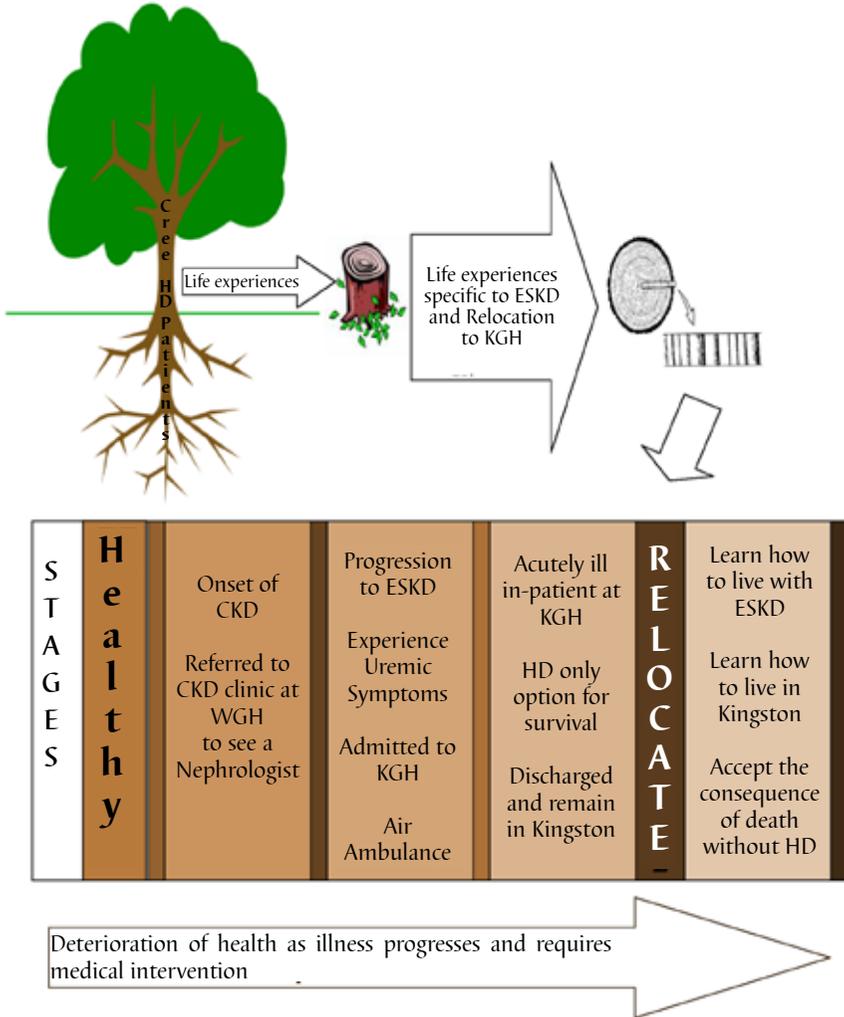


Figure 4: The co-created diagram from the HD patients tree analogy. The depiction of the stage of illness experienced by the HD patients regarding the progression of ESKD, requiring HD treatment. The “healthy” stage is situated at the inner-most ring of the tree trunk.

in Kingston, although it was not their ideal living situation. Ideal conditions that influence the tree's rate of growth and ultimately its survival could be interpreted as optimizing QoL (Figure 5).

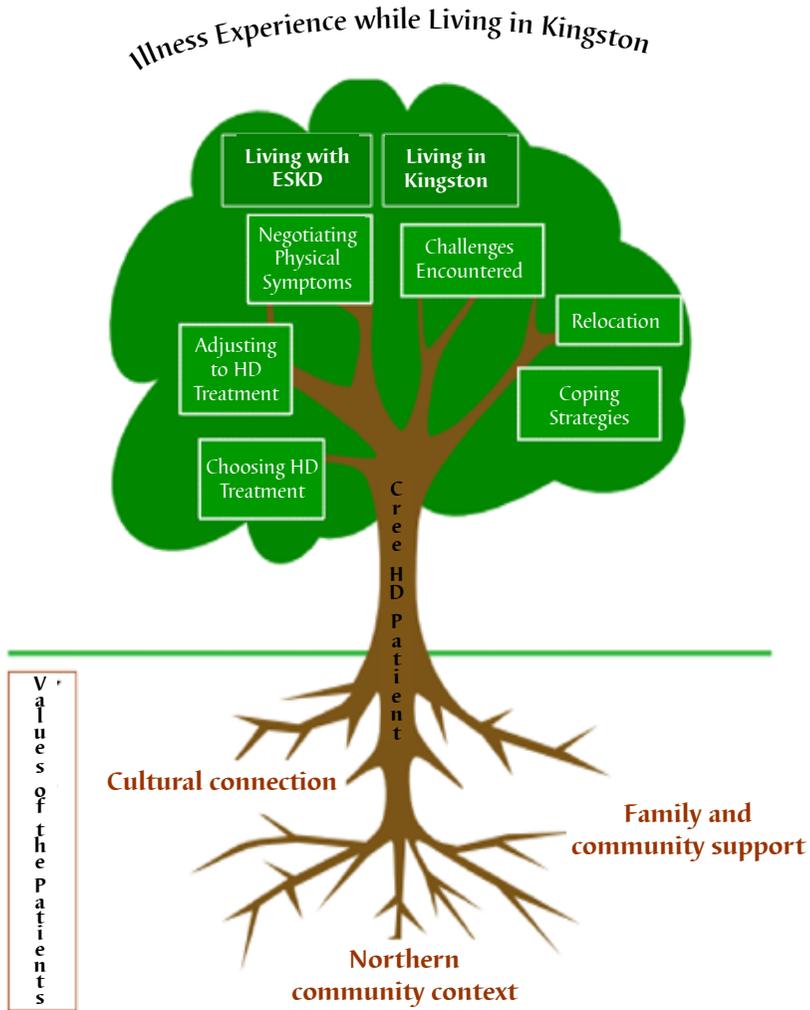


Figure 5: Diagram of analogy of QoL which HD patients identified as a tree which has been transplanted into the Kingston community.

Strength attained from family and community, culture and familiar Northern context were identified as 'grounding' the HD patients while living in Kingston. Their illness experience of receiving HD treatment in an urban context is identified by the core concepts of *Living with ESKD* and *Living in Kingston* with supporting themes.

DISCUSSION

This study presents important insight into the illness experience and perceived QoL of Cree from the Mushkegowuk Territory with ESKD who relocated to Kingston for HD treatment. For the Cree HD patients in this study, the life-altering effects of illness were manageable; however, the complexities of relocating to an urban environment, the deprivation of support and culture, as well as the intricacies of urban living, were felt to be insurmountable. This case study identified similar challenges described in the literature regarding the relocation of Aboriginal peoples to urban communities for HD treatment: cultural isolation, separation from family, financial burden of relocation, and establishment in an urban context. However, the study contributes new knowledge into the adjustment process for living with ESKD and receiving HD treatment, the divergent health beliefs between Cree HD patients and their healthcare providers in the context of Western health care, and the variables which influence QoL.

ILLNESS EXPERIENCE WHILE IN KINGSTON: THE INITIAL AND CHRONIC PHASES OF ADJUSTMENT

Remote satellite HD services in the Muskegowuk Territory did not exist at the time of this study; therefore, Cree individuals with ESKD had to relocate to Kingston in order to access life-sustaining HD treatment. When faced with a life-or-death choice, participants in this study chose to have HD treatment in Kingston. According to Braun-Curtin and colleagues (2002), this choice is identified as self-preservation, the conscious decision to keep living while negotiating the limitations imposed by life-sustaining HD treatment.

Healthcare providers, patient workers, and HD patients all believed that relocation to an urban centre for HD treatment was not the ideal method of service delivery for the Cree patients, but it was the only option. Inadequate organization of HD services and inaccessibility of renal units have been common themes in the literature that addresses Aboriginal relocation to access HD (Bennett et al., 1995; Devitt and McMasters, 1998; Salvalaggio et al., 2003; Wilson et al., 1994).

Initial phase: Adjustment to living with ESKD

Negotiating physical symptoms

The patients in this study were aware of the importance of HD treatment and attended their HD sessions regularly; a finding which concurs

with Bennett et al. (1995), but differs from Devitt and McMasters (1998). Physical symptoms, such as fatigue, muscle cramps, headaches, itchiness, weakness, and dizziness during and after their HD sessions, were reported by the patients, and are all commonly reported effects associated with HD treatment in both Aboriginal (Devitt and McMasters, 1998; Salvalaggio et al., 2003) and non-Aboriginal populations (Ersoy-Kart and Guldu, 2005; Frank et al., 2003).

Negotiating HD treatment has been identified as a significant alteration in lifestyle (Caress et al., 2001; Jablonski, 2004; Rittman et al., 1993). The impact of physical symptoms associated with ESKD and HD treatment on both Aboriginal and non-Aboriginal patients' daily living has been attributed to a negative illness experience due to the loss of independence (Bennett et al., 1995; Lindqvist et al., 2000; Salvalaggio et al., 2003), the loss of normalcy (Braun-Curtin et al., 2002; Caress et al., 2001; Lindqvist et al., 2000; Rittman et al., 1993), and the loss of freedom (Braun-Curtin et al., 2002; Ersoy-Kart and Guldu, 2005; Hagren et al., 2001; Krespi et al., 2004; Lindqvist et al., 2000; Rittman et al., 1993).

In the current study, HD patients associated their physical symptoms with the struggle to maintain daily fluid and dietary restrictions. The Cree patients' nonadherence to the dietary restrictions was influenced by a language barrier facilitated by the lack of health information written in Cree and their lack of familiarity with the nontraditional food selections. The discrepancy between medical requirements and the patients' actual food and fluid consumption have previously been demonstrated within populations receiving HD treatment, both Aboriginal (Devitt and McMasters, 1998) and non-Aboriginal (Braun-Curtin et al., 2002; Ersoy-Kart and Guldu, 2005; Gregory et al., 1998; Rittman et al., 1993). Subsequently, their behaviours were interpreted by healthcare providers as noncompliant or nonadherent. The reality of the HD patients' noncompliance to the fluid and food restrictions was more multifaceted than intentional nonadherence or disregard, and specifically influenced by the relocation to an urban context and the changes in food choices, as well as traditional and social food-related activities (Brown et al., 2008).

Adjustment to HD treatment

Acculturation occurred as the individuals in acute renal failure arrived in Kingston from the Mushkegowuk Territory, and they were admitted to KGH for HD treatment. No other study examining the impact of relocation to urban centres for HD treatment has identified the extreme state of health

in which participants commenced treatment (Bennett et al., 1995; Devitt and McMasters, 1998; Salvalaggio et al., 2003; Wilson et al., 1994). The HD patients in this study struggled with the realities of being hospitalized and requiring invasive HD treatment to live. The interactions and responses reported by the HD patients were similar to the culture shock of hospitalization as reported by Eckermann et al. (2006).

Rittman et al. (1993) noted a phase of adjustment for individuals requiring HD to familiarize themselves with the HD routine, procedures, and machines. For this study the adjustment phase was identified as acclimatization. A key aspect identified by the HD patients during acclimatization was the perceived lack of information given to them regarding their illness, HD sessions, and fluid and dietary restrictions. Their limited knowledge due to a lack of culturally appropriate resources increased their fear and anxiety, a finding that has been previously reported (Devitt and McMasters, 1998; Wilson et al., 1994). Language has been identified as a barrier to successful communication and knowledge translation in the literature regarding Aboriginal populations (Devitt and McMasters, 1998; Eckermann et al., 2006; Wilson et al., 1994). Strategies of knowledge acquisition identified by the HD patients in this study were observation, active listening, and asking questions of fellow patients and nurses.

Detachment was the third phase of adjustment for the patients who indicated that they felt invisible in their interactions with healthcare providers and depersonalized in the renal setting. Responses to stress and anxiety have been identified as avoidance and denial (Eckermann et al., 2006). Withdrawal, denial (Salvalaggio et al., 2003), and ambivalence (Devitt and McMasters, 1998) have been responses to HD treatment reported by Aboriginals and non-Aboriginals.

Acceptance, or the healing process, was identified as the final phase adjustment for Cree HD patients. Ultimately, the Cree HD patients struggled with the acceptance of their illness and relocation to Kingston. Both social supports and respect for cultural health beliefs were unavailable in the urban or renal care setting. Increased autonomy (Hagren et al., 2001) and self-efficacy during HD treatment (Braun-Curtin et al., 2002) are used to describe full adjustment or acceptance of treatment in non-Aboriginal HD patients; however, autonomy, self-efficacy, and increased engagement in relation to treatment were not demonstrated in this Cree HD patient population.

Chronic phase: Adjustment to living in Kingston

The illness experience of Cree HD patients in this study contained a chronic phase requiring adjustment to life in Kingston. As their health stabilized through adjusting to HD treatment, patients transitioned to the maintenance or chronic state of ESKD (Jablonski, 2004). This phase presented more challenges for the Cree HD patients than for their non-Cree counterparts, marked by significant changes in adjusting to the Kingston community. The HD patients continued to cope with ESKD and HD outside of the cultural and financial supports offered by the WHA and WPS. The urban context presented new challenges for Cree HD patients, who developed new coping strategies in response.

Relocation

The process of relocation to Kingston was fraught with logistical, emotional, and social complexities that intensified the differences between urban and remote contexts. Ultimately, the Cree HD patients perceived themselves as a more disadvantaged group within the larger Cree patient population from the Mushkegowuk Territory who were transferred to KGH for medical reasons. The relocation of individuals requiring HD is a common expectation for Aboriginal individuals living with ESKD, as demonstrated in the Canadian (Salvalaggio et al., 2003; Wilson et al., 1994) and Australian studies (Bennett et al., 1995; Devitt and McMasters, 1998).

Challenges encountered

While struggling with the daily physical challenges accompanying ESKD and HD treatment, the patients of this study grappled with the burden of establishing lives in Kingston and the isolation of living far away from everything and everyone they valued. In particular, securing finances and finding long-term accommodations were two of the logistical challenges encountered by patients. Difficulty in locating and securing accommodation for Aboriginal HD patients is a recurrent theme in the literature (Bennett et al., 1995; Devitt and McMasters, 1998; Salvalaggio et al., 2003; Wilson et al., 1994); however, the experiences of long-term accommodation options in apartments and hotels were less negative than the reported poverty-based, special-lease Aboriginal living areas or hostels depicted by Devitt and McMasters (1998) in Australia. Other indigenous populations relocating to urban centres for HD treatment reported receiving inadequate support, uncoordinated services, and limited resources (Bennett et al., 1995; Devitt and McMasters,

1998). The intricacies of funding of Aboriginal HD patients in Canada have not been previously reported in relation to illness experience and QoL.

Culture shock emerged in this study, identified elsewhere as displacement (Bennett et al., 1995), living in a strange country (Devitt and McMasters, 1998), and being out of place (Wilson et al., 1994). The comfort of familiar roles and family support counteracts culture shock, but these resources were not available for the patients who were relocated to Kingston.

Although HD treatment has been negatively identified as time consuming (Krespi et al., 2004), the HD patients in this study saw it as a means of filling their day-to-day lives while in Kingston. The uncertainty of their medical condition, the fluctuation in their physical health, and separation from family, friends, and community contributed to patients' inability to establish new roles in Kingston. Jablonski (2004) identified a similar characteristic in her proposed illness trajectory of individuals living with ESKD. The circumstance of being removed from former roles without establishing new roles in Kingston was characterized as being in limbo. Loss of meaningful roles, occupational independence, and employment have been reported for other indigenous and Aboriginal HD patients in Australia (Devitt and McMasters, 1998) and Canada (Salvalaggio et al., 2003). In this study, patients were distressed about their inability to participate in traditional meaningful community events and activities, thereby diminishing perceived well-being (Salvalaggio et al., 2003) and perceived health status (Wilson and Rosenberg, 2002).

Cree HD patients in Kingston perceived their separation from family as catastrophic. Studies examining the impact of relocation for HD treatment in the Aboriginal and indigenous population indicate that the relationships in the patients' lives were negatively affected (Bennett et al., 1995; Devitt and McMasters, 1998; Salvalaggio et al., 2003; Wilson et al., 1994). Reductions and disruptions in social supports (perceived or actual) over the course of illness have also been reported for non-Aboriginal populations (Braun-Curtin et al., 2002; Gregory et al., 1998; Hagren et al., 2001; Jablonski, 2004; Rittman et al., 1993; Rounds and Israel, 1985). The importance of family, friends, and traditions that has been identified as an inherent component of self-concept, perceived strength, and wellness for Aboriginal individuals (Van Uchelen et al., 1997) was missing for the Cree HD patients, resulting in a decreased perception of personal well-being and overall QoL.

Coping

The HD patients in this study relied upon social supports as their primary coping mechanism, and used the specific strategies of making return visits home, having visitors come to Kingston, and creating support networks in Kingston. Within the non-Aboriginal ESKD population, reliance on social supports and social networks have been identified as coping mechanisms (Gregory et al., 1998; Jablonski, 2004; Kimmel et al., 1996; 1998; Klang et al., 1996; Patel et al., 2002; Rounds and Israel, 1985).

HD patients in this study expressed a longing to return home, consistent with previous studies that explored the impact of relocation (Bennett et al., 1995; Devitt and McMasters, 1998; Salvalaggio et al., 2003; Wilson et al., 1994). Returning home was a vital experience, allowing the Cree HD patients to reconnect with family and friends in order to draw on replenished inner resources in Kingston. The Cree HD patients in this study referred explicitly to the positive relationship between living in their communities of origin and their survival, which is consistent with the findings of Wilson and Rosenberg (2002). On the negative side, three-day visits home had critical health implications due to missing HD sessions; nonetheless, patients considered the health hazards associated with return visits home to be worth the risk. Similar feelings have been expressed by indigenous individuals receiving HD treatment in urban centres (Bennett et al., 1995; Devitt and McMasters, 1998).

In the absence of family and friends, the Cree HD patients of this study formed a tightly knit group while in Kingston, consistent with findings on social supports and networks within renal units for non-Aboriginal patient populations (Gregory et al., 1998; Patel et al., 2002; Rittman et al., 1993; Rounds and Israel, 1985). Weeneebayko Patient Services workers were also perceived by the HD patients as social supports, acting as Cree cultural ambassadors and liaisons within the Kingston community and the medical environment. The HD patients viewed the WPSWs as primary facilitators of returning home and having visitors come to Kingston. Without each other, and the cultural connection facilitated by WPS, the Cree from the Mushkegowuk Territory receiving HD treatment would exist in a cultural vacuum in the Kingston and KGH communities, impoverished by the lack of cultural ties and bereft of social support.

Overall, the adjustment of the Cree patients in this study to both ESKD and HD treatment was reported to be difficult, although manageable, in

comparison to the social deprivation and cultural isolation they experienced. The additional fear and anxiety of being alone inhibited the healing process, according to the HD patients of this study. The delivery of HD treatment for Aboriginal and indigenous peoples should be made accessible to patients in a culturally congruent environment in which they feel safe and supported; this may facilitate the healing process over the continuum of chronic renal failure.

Divergence of Cree and healthcare provider health beliefs impact clinical interactions

A novel contribution of this study to the current literature is the conceptualization and presentation of the health beliefs of the Cree HD patient regarding ESKD, illness experience, and perceived QoL. Divergence of health beliefs of the Cree HD patients and their healthcare providers fostered misconceptions, which in turn affected communication and ultimately clinical interactions. The coexistence of divergent viewpoints between traditional health beliefs and contemporary medical beliefs has been explored with Aboriginal individuals seeking health care services and treatment (Devitt and McMasters, 1998; Eckermann et al., 2006; Van Uchelen et al., 1997; Willis, 1995).

Health beliefs and perspectives regarding the origins of kidney disease have not been reported for the Cree of northeastern Ontario. Disrespecting spirits was recognized as the potential cause of general illness, but not specifically for kidney disease. They expressed their belief that everything has a spirit, and that punishment for disrespectful actions towards spirits can result in illness. The concept of retribution from a divine source within a religious orientation has been demonstrated in research with non-Aboriginal participants (Caress et al., 2001; Lindqvist et al., 2000). Aboriginal HD patients identify biological and physiological conditions as the causes for their ESKD, including infection, heredity, complication at birth, and high blood pressure (Krespi et al., 2004). Furthermore, the Cree HD patients identified a lack of balance in their lives regarding their isolation from family, community, and culture that can be interpreted by spirits as intentional disrespect, which may contribute to acquisition of an illness.

The bond between mind, body, and spirit identified in this study has not been previously explored in kidney disease literature regarding Aboriginal health beliefs. In studies of non-Aboriginal populations living with ESKD (Braun-Curtin et al., 2002; Gregory et al., 1998; Hagren et al., 2001; Rittman

et al., 1993), the role of each domain — mind, body, and spirit — was explored in relation to the adjustment to living with ESKD and HD treatment, which can be equated to acceptance of illness.

Van Uchelen and colleagues (1997) explored the components of well-being in urban Aboriginal Canadians with diabetes and found that lack of respect and lack of cultural identity were believed to be the causes of illness, while wellness was associated with an individuals' connection to others, the earth, spirits, and respect. A spirit component, specifically within the traditional beliefs system, has been associated with wellness in the Aboriginal ESKD population (Devitt and McMasters, 1998; Salvalaggio et al., 2003). The HD patients in this study also demonstrated a belief in connectedness, specifically, an intergenerational and interpersonal link. Patients indicated that the consequences of one individual's action could affect many others, even down through the generations of a family. Interconnectedness is in agreement with the collectivistic beliefs reported in the orientation of Aboriginal peoples (Eckermann et al., 2006; Throne, 1993; Van Uchelen et al., 1997). Failing to address the spirit or disregarding traditional beliefs in a renal care program is potentially detrimental to Aboriginal HD patients. Culturally oriented health beliefs require attention and consideration because they strongly influence the Aboriginal HD patients' ability to adjust and accept both their illness and its treatment.

Implications of the divergent health beliefs can be demonstrated in the Cree patients' and healthcare providers' perspectives regarding fluid and dietary restrictions. Patients acknowledged the dietary and fluid restrictions but did not demonstrate an in-depth knowledge of them. Lack of culturally appropriate resources explaining ESKD, HD treatment, and dietary instruction with respect to traditional foods hampered the patients' ability to follow the treatment guidelines.

Cultural differences in communication style prevented HD patients from initiating conversations with healthcare providers or inquiring about further resources or assistance. Healthcare providers interpreted these characteristics of communication as ambivalence, which has been discussed within the Aboriginal ESKD population and their health-related decision making (Devitt and McMasters, 1998; Salvalaggio et al., 2003), and linked to a manifestation of the divergence between traditional health beliefs and modern medicine. Nephrologists and nephrology nurses acknowledged that dietary and fluid instructions were provided to each patient in the Renal Unit, and indicated that dietary restrictions were rarely followed by the Cree

HD patients. The cultural communication gap prevented the healthcare providers and the HD patients from finding a common point upon which they could base their interaction to promote knowledge translation.

Although the cultural divergences in health beliefs cannot be negated in the health care practices or settings, they can be mediated by cultural awareness and culturally appropriate practices. Educating healthcare providers and assisting Cree HD patients' adjustment to living with ESKD via culturally relevant resources will assist in bridging the current gap of knowledge currently creating misconceptions and affecting the chance of optimal care.

The negative implications of relocation to Kingston on perceived quality of life of Cree HD patients

Participant groups in this study offered divergent views on the components of QoL. Nephrologists described QoL as the absence of an illness and the presence of physical, mental, and emotional stability. Nurses added the constructs of spirituality and control to the definition of health. The healthcare providers' definitions of QoL were consistent with the Western health beliefs and a medical perspective of disability (Brant-Castellano, 2004; McColl and Bickenbach, 1998; Throne, 1993). Weeneebayko Patient Services workers similarly identified an absence of illness, but contributed the idea of a healing process that must be completed. The WPSWs offered "well-being" as a synonym for QoL, as did the Cree HD patients.

The HD patients reported a holistic orientation to QoL which included two constructs: respect and the mind-body-spirit connection. The Cree HD patients conceived of QoL as collective and naturalistic. Specific variables that contributed to the patients' QoL were emphasized: connection to others, to traditional culture, to the earth, and to the spiritual realm, which was consistent with the literature exploring components of Aboriginal health beliefs (Eckermann et al., 2006; Olson, 2001; Throne, 1993; Van Uchelen et al., 1997). From the patients' descriptions of respect and the mind-body-spirit connection, it is obvious that physical, emotional, and social insults to their self-respect were endured in the medical environment and the community during the illness experience. As explained by the HD patients and the WPSWs, if an individual's spirit is not acknowledged, supported and included in their medical regime, the procedures that are directed to their bodies or their minds will not be successful.

CONCLUSION

Living with ESKD has been identified as a life-altering experience by the Cree HD patients. They felt restricted by a regimented set of medical guidelines affecting their daily lives that were designed to achieve optimal outcomes in their HD treatments.

Physical symptoms were directly linked to the patients' difficulty adhering to fluid and dietary restrictions. Physical abilities of the patients deteriorated due to the effect of both the uremic symptoms and HD treatment. For the Cree HD patients, the life-altering effects of illness, the complexities of relocation, the deprivation of support and culture, as well as the intricacies of urban living, were insurmountable. The illness experience of the Cree HD patients made their perceived QoL significantly worse when they relocated to Kingston for life-sustaining HD treatment.

While the goal of this study was to explore the illness experience, the concept of QoL and divergent health beliefs became apparent between healthcare providers and Cree HD patients. A dichotomy of disease management originating from health beliefs, related behaviours, and social variables compromised the Cree HD patients' adjustment and adherence to treatment regimes and their relationships with healthcare providers. Misperceptions of the beliefs and behaviours of Cree HD patients negatively affected clinical interactions. Further exploration into culturally appropriate communication strategies, as well as ESKD and HD education resources, would benefit knowledge translation for both patient and healthcare provider.

The permanent relocation to a different geographic area, an unfamiliar territory, and a foreign way of life for Aboriginal individuals requiring HD treatment can be alleviated by HD treatment being offered at rural or remote satellite dialysis services. A paucity of information exists in the literature about the implications of satellite dialysis services being established in remote communities. Further exploration into the illness experiences, the perceived quality of life, and logistical management of remote HD satellite services is required.

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