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Perspectives on health: experiences of First Nations dialysis patients relocated from remote communities for treatment

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Objective: To explore the experience of health and illness among First Nations dialysis patients. Design: Qualitative descriptive study using semi-structured interviews. Setting: Thunder Bay Regional Hospital Renal Service, Thunder Bay, Ont. Participants: Twelve self-declared First Nations patients receiving either peritoneal dialysis or hemodialysis. The Nishnawbe–Aski Nation participated in the development, review, and dissemination of the study. Methods: Interviews were conducted with participants in either English or Oji–Cree, with an interpreter on hand where necessary. All interviews were audiotaped and transcribed verbatim. Transcripts were subjected to immersion/crystallization analysis by 3 researchers. Theoretical saturation led to the development of 4 major themes. Research findings were represented to participants and community partners. Results: Four major themes related to the dialysis experience emerged: 1) somatic issues, 2) loss of independence,
3) impact on relationships, and 4) psychological adjustment. Conclusion: First Nations dialysis patients face symptomatic, functional, interpersonal and psychological challenges; becoming sick and receiving treatment is a multidimensional experience.

Objectif : Étudier l'expérience de la santé et de la maladie chez des membres des Premières nations en dialyse. Conception : Étude descriptive qualitative faisant appel à des entrevues semi- structurées. Contexte : Service de dialyse de l'Hôpital régional de Thunder Bay, Thunder Bay (Ont.). Participants : Douze personnes se déclarant membres des Premières nations et recevant un traitement par dialyse péritonéale ou par hémodialyse. La Nation Nishnawbe– Aski a participé à

l'élaboration, à l'examen et à la diffusion de l'étude.
Méthodes : On a interviewé les participants en anglais ou en oji–cri et un interprète était disponible au besoin. Toutes les entrevues ont été enregistrées sur bande sonore et transcrites textuellement. Trois chercheurs ont soumis les comptes rendus à des analyses par immersion-cristallisation. Quatre grands thèmes se sont dégagés de la saturation théorique. Les résultats de recherche ont été présentés aux participants et aux partenaires de la communauté. Résultats : Il est ressorti quatre grands thèmes relatifs à l'expérience de la dialyse : 1) les aspects somatiques; 2) la perte d'autonomie; 3) les conséquences sur les relations; 4) l'adaptation psychologique. Conclusion : Les membres des Premières nations qui sont en dialyse sont confrontés à des défis sur le plan symptomatique, fonctionnel, interpersonnel et psychologique. L'apparition de la maladie et le traitement constituent une expérience multidimensionnelle.

Introduction

Canada's First Nations population has 3 times1–3 the rate of end-stage renal disease (ESRD) than the non-aboriginal population. The prevalence of this chronic illness reflects higher rates of type 2 diabetes4 and glomerulonephritis.5 Unless a donor kidney for renal transplant is available, ESRD requires chronic renal dialysis. Although continuous ambulatory peritoneal dialysis is an option for some individuals, it requires medical support, extensive patient education and commitment, as well as adequate community water supplies and sanitation facilities. Such conditions are often unavailable in smaller, more remote communities. Hemodialysis requires additional resources, such as trained personnel and dialysis machines. As a result, First Nations dialysis patients often have very little choice but to leave their communities and relocate to larger, urban centres. The authors of this study wanted to understand this experience.

Several studies have addressed the experience of illness of First Nations dialysis patients through their exploration of decision-making issues6 and the impact of relocation.7 It has been suggested that isolation, unemployment and lack of familiarity with the health care system play larger roles for First Nations patients than for the general population.8,9 Divergent concepts of health and patient priorities can make cross-cultural challenges interesting; cultural context and rules of behaviour may not be explicit.10 Language barriers and time constraints may further hamper cross-cultural understanding.11–13

Clare Brant, a Mohawk psychiatrist, outlined a set of Native rules of behaviour,

including the principles of non-interference, noncompetitiveness, emotional restraint, sharing, teaching by modelling, altered protocol, and unique concepts of time.10 Other clinicians have described altered communication styles with First Nations patients; patience, comfort with silence, listening, storytelling and humour are among the elements often encountered.14 Recent publications addressing the ethics of research among First Nations emphasize the need for community participation. Externally driven, quantitative survey-type methodology is considered unacceptable.15–17 In this context, it was felt that a qualitative descriptive study would best document First Nations dialysis patients' experience.

Objective

The objective of this qualitative study was to explore the experience of health and illness among First Nations dialysis patients in Northwestern Ontario.

Methods

Design

Qualitative research methodology was used to explore participants' attitudes and experiences in depth. More familiar quantitative approaches (e.g., surveys) are recognized as being inadequate for First Nations research.15 A series of questions for use in semi-structured interviews were developed in consultation with the health office of the Nishnawbe–Aski Nation (NAN). This Ontario nonprofit corporation is mandated by the Chiefs of 46 First Nations communities across Northern Ontario to represent their communities' health, economic and social interests. The questions dealt with the meaning, causes and consequences of health and illness, as well as the actual dialysis experience. The questions were reviewed by research peers, several First Nations interpreters, and the Lakehead University Department of Native Studies in Thunder Bay, Ont. Translations into Oji–Cree were agreed upon by 2 interpreters.

The study was approved by the Thunder Bay Regional Hospital Research Ethics Committee as well as by the Nishnawbe–Aski Nation.

Data gathering

Patients eligible for the study included all self-declared First Nations individuals receiving either peritoneal dialysis or hemodialysis through the Thunder Bay

Regional Hospital Renal Service. Interview subjects were chosen based on their likely willingness to share their stories. Permission to approach potential participants was obtained by their nurses. The research study was described, and informed written consent was obtained. Confidential one-hour interviews were conducted by one of the authors (G.S.) on the dialysis unit or in another venue, with or without an interpreter, according to participant preference. Interviews were audio-taped and transcribed verbatim, and were supplemented by field notes.

Data analysis

The immersion/crystallization method was chosen for data analysis. This qualitative approach consists of repeated cycles of "prolonged immersion into and experience of the text and then emergence, after concerned reflection, with an intuitive crystallization of the data."18 Analysis occurred during and after the data collection stage using field notes as well as QSR NUD*IST qualitative analysis software (QSR International).

Validity of the data set and subsequent analysis was tested in a number of ways. The interviewer did not speak Oji–Cree; translated interviews were reviewed and verified by a second interpreter. Themes that evolved early on in the analytical process were tested in subsequent interviews with probe questions. Confirming and deconfirming cases were sought until the interview content did not appear to yield any new thematic material. Triangulation of analysis of each interview with 2 other researchers limited the effect of personal bias by the interviewer. Finally, dissemination to research participants, the renal service, and NAN allowed for "member checking," a qualitative validity technique.

Participants

Twelve dialysis patients were interviewed over a 5-month period. Eight interviews were conducted in English and 4 in Oji–Cree. Participants ranged in age from 19 to 73 years. There were 3 men and 9 women. Communities of origin were widespread throughout Northwestern Ontario. Seven individuals identified communities of origin accessible by air only. Disease processes leading to dialysis were also variable; the majority had type 2 diabetes. Participants had spent anywhere from 6 months to more than 5 years on dialysis. Three people were on peritoneal dialysis, and 9 were on hemodialysis at the time of the interview.

Results

Dialysis had a tremendous impact on many facets of the participants' lives. Four major themes emerged as essential interdependent elements of the experience, and indeed contributed to one another: 1) somatic issues, 2) loss of independence, 3) impact on relationships, and 4) psychological adjustment.

Somatic issues

Dialysis patients disclosed significant physical symptoms. These in turn had an impact on the quality of life of participants. Many individuals identified weakness and fatigue as a major adverse effect of treatment. Patients described increased difficulty carrying out activities of daily living.

"Being sick to me is if I'm flat on my back and I can't get up."

A number of participants felt that the frequent experience of pain during the course of their illness and treatment altered their ability to carry out formerly easy tasks and to enjoy life. Some feared further pain and its consequences.

"I'm so sick and tired of being so sore . . ."

Nausea, loss of appetite and dietary restriction reduced the enjoyment of eating. Necessary diet modifications were perceived to be restrictive, and noncompliance resulted in nausea and discomfort. Other physical symptoms surfaced (e.g., shortness of breath, body swelling, abnormal smells or tastes).

"Loss of independence

A loss of independence was universally described. Function was very important to participants. Self-sufficiency was often threatened; participants felt that they were creating a burden for others.

"Being sick is when you can't even help yourself any more. . . . You can't wash your clothes or clean up your house and you don't have the energy to do anything. That's what sick is."

Limitation of physical mobility figured prominently. Patients felt that their bodies had lost strength and would not allow them to carry out their premorbid activities in the same way.

"It's slowly failing that's all. I used to be able to walk about from [the other end of town] to here . . . I still can do it, but I gotta take a lot of sit downs to let [my] legs rest."

While a lack of activity was equated with illness, maintenance of activity, on the other hand, was perceived to be beneficial to health.

"When I feel better a little bit . . . I always try to take a walk. Walk. That's the only way I'm supposed to move around. If I don't do it, I'll just be stuck. . . . like they say . . . our blood doesn't circulate when we stop. Only when we're moving, that's the only time it moves. When we stop, everything stops."

Occupational independence was highly treasured and greatly missed. Patients missed being able to work and contribute to their communities and families. Many had attempted to keep as busy as possible but resented the loss of a defined role.

Economic loss resulted from unemployment, physical disability and relocation. A low income resulted in several concerns related to housing; participants had to deal with limited storage space, loss of privacy and poor security. Individuals found it difficult to live within their budgetary constraints.

"I loved to work. I was working before . . . before I moved here. . . . at least I didn't have to go on welfare [laughing]. . . . I can't get anything . . . buy anything. . . . I used to buy [my daughter] lots of things but now I have to watch our budget."

Limited income intensified many patients' separation from their home communities. Travel in the North is expensive, and patients were unable to afford regular visits with family and friends.

"They're being pulled out from their home without any assistance and they have to try and adjust, especially the ones that haven't . . . that's never been . . . away from home before . . . a lot of people can't go home because they can't afford it."

Dialysis also limited recreational pursuits. Premorbid recreation typically consisted of outdoor, land-based activities such as hunting, fishing and camping. Many fond memories of a more peaceful, quiet time surfaced. Participants felt that they could not enjoy such activities to the same extent in the urban environment.

"Because I like to sit . . . sit out there in the bush. Think. Relax . . . without any

noise."

These traditional recreational activities were associated with social well-being and felt to be a consequence of good health. "I like when my kids spend time with me, do things for me. It makes me alive. Or if we go picking somewhere in the bush. I feel better. A lot better. Or if there's camping. I like it. I miss all those things."

Impact on relationships

While participants emphasized the importance of individual function, they also valued their relationships. Dialysis not only led to physical separation from friends and family but also changed patients' ability to socialize and live up to former roles within these relationships.

Participants with children felt lonely without them; when they were able to visit, the hardships of dialysis were minimized and quality of life improved.

"When my kids are in town I feel . . . better. I can feel myself."

Children were equally affected by their parents' illness. Participants worried about the ability of their children to cope on their own. Others felt that some role reversal had taken place, and that children were now taking care of their parents. Participants felt distanced from other family members also and believed that their presence, especially at the time of relocation, would be helpful. Some worried about their inability to support elderly parents and partners.

"My husband is not well either . . . I worry about him too. Right now, it's just the two of us at home."

Friendships in home communities were recalled. Laughter and play were common ingredients in these friendships and allowed patients to better cope with illness and remain connected to the community.

"I'd walk down to my friend's place. . . . Maybe we'd go play cards. . . . We used to have a lot of fun. . . . We used to go to powwows. We used to go to powwow trails."

Some patients experienced alienation from their former friends. They felt stigmatized by their illness.

"I don't have any friends [laughing] any more. I used to have . . . lots of friends. But I guess they're . . . kind of scared of this disease or something."

Psychological adjustment

Dialysis patients experienced a wide variety of psychological changes as well, as might be expected with a population at different stages of change. They described emotional reactions consistent with grief and loss -- sadness, boredom and depression.

"At the beginning it was okay. It didn't bother me. Now it's . . . I'm getting down, down, down."

Conversely, others reacted with denial. Noncompliance with treatment occasionally resulted.

Although withdrawal behaviour was prevalent, many patients reacted with anger and frustration. Occasionally this anger translated itself into blame.

"I blame my daughter . . . she . . . let [the doctor] put that catheter on. . . . I didn't want it in. I told them 'I don't want it in right now. . . . When I'm good and ready, I'll let you know.' "

Participants endured a lot of uncertainty. They experienced worrisome physical symptoms, underwent numerous diagnostic investigations and travelled great distances with many unanswered questions. Participants struggled with a loss of autonomy over treatment decisions.

"All my friends were asking me, 'What's wrong with you? Look at your face! [It] is all swollen! Look at your hands! Look at your legs. Everything is all swollen. What are they doing to you?' I said, 'I don't know what the white people are doing to me in Thunder Bay. They're drowning me with their water.' "

Mortality was another issue. The onset of ESRD and the need for life support from dialysis reinforced the notion that death could come with very little warning.

" . . . they [i.e., death] might call on me today, maybe in an hour or something you know? And I don't like to leave when I have bitter feelings, or an angry feeling or .

. . you know?"

Coping strategies were developed to manage these feelings of uncertainty and loss. Many participants indicated that happiness was essential to health. Humour and laughter were used to tell stories during the interviews. Visits with friends permitted the sharing of happy memories. Many believed in the importance of a positive focus. Gratitude and hope helped alleviate the suffering.

"In a way, I'm luckier than some of them. . . . When I start worrying about how I am, I look at other people. I see them with their feet off, or almost right up to their waist with no legs and I think I'm luckier."

For some, this optimism encouraged active participation in their care, through better lifestyle management or the assumption of nursing and housekeeping tasks.

Several individuals acknowledged that spirituality played a role in their lives. For some, traditional ways were central to wellness. One participant felt that pride in her culture and language and faith in her people's medicines was the only way to get through her illness. For another, a Christian philosophy prevailed, and faith in God was paramount to emotional survival.

"I just about died a few times. God's . . . looked after me and He pulled me through."

Discussion

The authors came away with a better understanding of the dialysis experience of a First Nations patient, including, but not limited to, physical symptoms, loss of independence, altered interactions with family and friends, and psychological adaptation to illness. Although many of our findings might be expected intuitively, the experiences of these patients have not been clearly documented in the past. It is hoped that our results can clarify the important elements of the dialysis experience for both patients and their caregivers.

Our findings are consistent with those of similar studies. Wilson and colleagues>7 examined the effects of relocation for dialysis in the Moose Factory Zone; subjects expressed concerns about increased expenses, housing inadequacies, family separation and a lack of control over health care decisions. Kaufert and coworkers>6 found that First Nations ESRD patients experienced uncertainty about

their diagnosis, loss of freedom and an inability to contribute to their communities. Hospitalized First Nations individuals interviewed in another Thunder Bay study identified physical, emotional and functional facets of health, illness and healing (Homeniuk S, Knutson G, Wrigley M. Aboriginal patients' views of health and nursing. Unpublished observations, 1996). Physical and social limitations, uncertainty about the future and depression are also prominent themes in studies involving ESRD patients of non-First Nations descent. However, the latter group preferred problem-solving as opposed to affective measures for use as coping strategies.>19,20 Our study's findings are unique in their emphasis on familial separation and functional loss -- particularly physical mobility and untoward physical symptoms.

Participants described a range of internal reactions and subsequent adjustments to their situation. Traditional spirituality played a role for only some patients; this finding may reflect the variable experience of Western acculturation and traditional cultural preservation in First Nations communities.>21 Given this diversity, patient perspectives on these matters must be approached within a patient-centred paradigm.

The study findings also have several administrative implications. A greater focus on occupational therapy and physiotherapy, with particular attention to physical mobility, could help to alleviate functional loss. Recreational therapy programs could provide opportunities to enjoy premorbid, land-based activities in a new setting. Access to family medicine, social work and cultural liaison services -- before, during and after the transition to an urban setting -- would help to ensure that individual needs are met in other areas. Financial support for housing and travel arrangements could significantly decrease the impact of relocation. The notion of satellite units closer to home communities has also been entertained as a way to minimize this separation. Finally, patient-driven education and support groups have been advocated in similar qualitative studies and could serve to improve overall quality of life.22,23

Limitations

The fatigue and discomfort caused by ESRD and the noise and distractions of dialysis treatments may have limited the responses of some participants. Cultural limitations were also present. A Western study method was used by a non-First Nations research team. Researchers had to be mindful of cross-cultural differences in ethical rules while conducting field work. Where added language barriers existed, an interpreter acted as an intermediary. Interpreters served not only as

translators, but also as culture brokers, informants and patient advocates.11Attempts to minimize these limitations included a literature review of cross-cultural communication issues, frequent assessment of interview technique, the use of open-ended questions, a relaxed time frame, regular debriefing with interpreters and advice and participation from First Nations individuals and NAN representatives.

Areas for further study

An exploration of function and mobility might lend greater insight into the effects of functional loss. Patient recommendations for improvements to their care remain conjecture at present and could be elicited. Focus groups or "sharing circles" might be an ideal setting in which to explore the experience of dialysis from the perspective of patients and family and community members. The relatively undocumented nature of urban Aboriginal communities might also be discussed in this way in an attempt to help ESRD patients from rural areas adjust.

Conclusions

The richness of the stories we encountered suggests that health and illness encompass a breadth of experience much greater than that of diagnosis and treatment of disease. Acknowledging the symptomatic, functional, interpersonal and psychological challenges faced by First Nations dialysis patients may allow both clinicians and patients to better understand the experience.

Competing interests: None declared.

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