

Native Canadians relocating for renal dialysis

Psychosocial and cultural issues

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OBJECTIVE To examine the effects of relocation from remote Native communities for dialysis treatment and explore the receptiveness of patients, caregivers, and their communities to establishing a local satellite dialysis unit. Second, to examine the methodological issues inherent in a qualitative, cross-cultural study.

DESIGN Qualitative descriptive survey using semistructured interviews.

SETTING The Moose Factory Zone (MFZ), situated along the west coast of James Bay in northern Ontario, is one of four geographically defined areas of responsibility within Ontario through which the federal government provides health care services to Native Canadians.

PARTICIPANTS Twenty-four Native residents of MFZ selected by volunteer and nominative sampling techniques. Patients with end-stage or prefailure renal disease, informal caregivers and supporters, professional caregivers, and community spokespersons were included in the study population.

MAIN OUTCOME MEASURES Identification of issues important in planning dialysis services for Native patients in remote communities in the MFZ.

RESULTS Informal caregivers and both categories of patients supported in principle a proposed satellite dialysis unit at Moose Factory General Hospital. Their criticisms of the present system necessitating relocation to urban centres included inadequate social support, inconvenience and expense, and family separation. Professional caregivers generally supported establishing a local dialysis unit but had concerns regarding staff training and continuity of care. Community spokespersons also supported the proposed unit but only if quality of care could be ensured.

CONCLUSIONS Relocation for dialysis treatment disrupts social support patterns and creates psychosocial problems. Although the psychosocial advantages of providing dialysis treatment services close to home are readily apparent, other considerations, such as cost, equipment, and expertise, and training of health care personnel, make the provision of tertiary level care more difficult in isolated areas. Additional study is required to determine the impact of methodological issues inherent in qualitative cross-cultural studies such as this.

OBJECTIF Examiner les conséquences résultant du déplacement des Autochtones de leur communauté éloignée pour obtenir des traitements de dialyse et explorer la réceptivité des patients, des soignants et de leurs communautés à la mise sur pied d'unités de dialyse satellites et locales. Deuxièmement, examiner les aspects méthodologiques inhérents à une étude qualitative et transculturelle.

CONCEPTION Enquête descriptive qualitative utilisant des entrevues semi-structurées.

CONTEXTE Moose Factory Zone (MFZ), située le long de la côte ouest de la Baie James dans le nord de l'Ontario, constitue l'une des quatre régions ontariennes délimitées géographiquement où le gouvernement fédéral dispense des soins de santé aux Autochtones canadiens.

PARTICIPANTS Vingt-quatre Autochtones résidants de la MFZ sélectionnés par des techniques d'échantillonnage volontaires et nominatives. La population étudiée comprenait des patients en préinsuffisance rénale ou atteints de néphropathie terminale, le personnel de soutien, les soignants, les professionnels de la santé et les porte-parole de la communauté.

PRINCIPALES MESURES DES RÉSULTATS Identification des aspects importants reliés à la planification des services de dialyse destinés aux Autochtones vivant dans les communautés éloignées de la MFZ.

RÉSULTATS Les soignants informels et les deux catégories de patients étaient en principe d'accord avec la proposition de mettre sur pied une unité satellite de dialyse à l'Hôpital général de Moose Factory. Parmi leurs critiques du système actuel obligeant un déplacement dans les centres urbains, notons l'insuffisance du soutien social, les inconvénients, les dépenses et la séparation de la famille. Les soignants professionnels étaient en général d'accord avec la mise sur pied d'une unité locale de dialyse mais ont exprimé des inquiétudes concernant la formation du personnel et la continuité des

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soins. Les porte-parole de la communauté appuyaient également l'unité proposée mais seulement si on pouvait garantir la qualité des soins.

CONCLUSIONS La relocalisation pour fins de dialyse perturbe l'organisation des soutiens sociaux et crée des problèmes psychologiques. Malgré l'évidence des avantages psychosociaux reliés à l'accès aux services de dialyse à proximité du domicile, d'autres considérations telles le coût, l'équipement, la compétence et la formation du personnel rendent la dispensation des soins de niveau tertiaire plus difficile dans les régions isolées. Des études supplémentaires sont nécessaires pour déterminer l'impact des aspects méthodologiques inhérents aux études qualitatives et transculturelles comme celle-ci.

Can Fam Physician 1994;40:1934-1941.

PREVALENCE RATES FOR END-STAGE renal disease (ESRD) among Native* Canadians far exceed those for Canadians as a whole. In a nation-wide survey, Native age-standardized ESRD incidence rates were determined to be 2.4 to 4 times greater than those for the nation.¹ As well, Natives with diabetes are at least twice as likely to progress to ESRD as non-Natives with diabetes, and the incidence of diabetes among Native groups in Canada and the United States has frequently been shown to be in excess of non-Native rates.²⁻⁵

Several issues surround the planning of services for this population group. Currently, Natives with ESRD who live in remote areas must be relocated to large urban centres for their dialysis treatment. This necessary upheaval disrupts social support patterns and creates myriad psychosocial and cultural problems. Concerns about relocating Natives to unfamiliar urban centres are substantiated by research documenting the compounding effects of stressful urban adaptation requirements on illness.⁶⁻⁸ An urban health care system that is unfamiliar and that lacks sensitivity to Native culture limits the potential for health promotive behaviour, which ultimately has adverse effects on

*Native is used throughout this article to refer to the indigenous and aboriginal inhabitants of Canada and their descendants. Status Indians is used to refer to Natives registered with the federal government as Indians according to the terms of the Indian Act, non-Status Indians to refer to Natives not registered with the government, and Inuit to refer to the Native peoples of the Arctic.

compliance and thus treatment outcome.^{9,10}

The excessive burden of illness suffered by Native people is further complicated by difficulties in providing tertiary levels of care (dialysis or transplant) to patients living in geographically isolated, small, northern communities. Although the psychosocial advantages of providing services close to home are readily apparent, other considerations, such as cost, training of health care personnel, equipment, and technical and specialist support, make providing tertiary level care more difficult in isolated areas. However, success with home and satellite dialysis programs in other regions has led planners to consider developing such programs in isolated communities.

METHODS

Study setting

Health care for Natives, a responsibility of the federal government, is administered by the Medical Services Branch of Health Canada through a regional system. Moose Factory Zone (MFZ), located along the west coast of James Bay, is one of four zones within Ontario. Queen's University in Kingston, Ont, has a 28-year history of involvement in health care delivery in this area.¹¹ Currently, patients requiring hemodialysis must relocate to a larger centre, usually Kingston. The need for this study was identified by the Mushkegowuk Tribal Council and the MFZ Medical Director of the Ontario Medical Services Branch.

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Objectives

This paper reports one aspect of a larger study conducted among the James Bay Cree during the summer of 1990. The first part of the study, previously published,¹² determined the prevalence of ESRD in the James Bay Cree to be 3.2 times the national rate. The average annual incidence rates for 1980-1989 were 1.8 times the national

techniques were used to determine the study sample.¹³ Potential informants were initially identified by accessing the medical records of Moose Factory General Hospital. Other potential informants were identified by the Medical Services Branch Director or Mushkegowuk Tribal Council.

These individuals were then approached by the primary researchers, two female non-Native medical students, who explained the purpose of the study and requested participation. However, the process began to snowball, and further informants were recommended by others in the study. The strength of the snowball sampling technique in a small, culturally distinct community is that those within the group can recognize knowledgeable "insiders" who can provide valuable information to researchers.

Patient informants had a mean age of 55 years (range 16 to 79 years). Three of the patient informants were male and four were female. Of the remaining 17 informants, seven were male and 10 were female.

The informants interviewed during field work in the summer of 1990 represented a variety of perspectives. *Table 1* provides the inclusion criteria and selection method for each type of informant. Twenty-four key informant interviews were conducted. Five categories of informants were approached: ESRD patients (4); prefailure renal disease patients (3); informal caregivers and supporters (7); professional caregivers, who included nurses, mental health workers, and physicians (8); and community spokespersons (2).

Data gathering

All interviews took place after informed signed consent was obtained and were held either in a health care centre or in informants' homes, at the convenience of the informants. Interviews lasted approximately 1 hour, and four informant interviews required translation. Data were collected for analysis using two approaches. First, the interviews were recorded on

Table 1. Categories of informants: How respondents were identified

PEOPLE WITH END-STAGE RENAL DISEASE: those people identified by review of records to have had either chronic or acute renal failure that required treatment by dialysis or transplantation for any period.

PEOPLE WITH PREFAILURE RENAL DISEASE: those people identified by review of records to have had some degree of renal failure but whose kidney status had not yet deteriorated to the point where dialysis or transplantation was required. In some cases it was clear that the informant was undoubtedly progressing to end-stage failure; in others the prognosis was less certain.

INFORMAL CAREGIVERS AND SUPPORT PERSONS: those people identified by observation, informal discussion, or self-identification to have provided or be providing care or support to the person with renal disease (family members, friends, church organizations, etc)

PROFESSIONAL CAREGIVERS: those people identified by the hospital medical director to be involved in the present care of persons with renal disease or who will be involved in or affected by possible treatment program changes.

COMMUNITY SPOKESPERSONS: those people identified by title or generally recognized to represent the interests and views of their respective communities.

rate. The second part of the study, also carried out during the summer of 1990 and reported in this article, aimed to examine the disruptions created by relocation for dialysis treatment and to explore the receptiveness of patients, caregivers, and their communities to establishment of a local satellite dialysis unit. We also attempted to elucidate other factors, such as cost, training, and perceived quality of care, that could have affected the willingness to establish a local hemodialysis unit. Methodological issues inherent in cross-cultural qualitative studies such as this were also examined.

Study population

Informants in the study population were Status Indians residing in the MFZ, both on and off local reserves. Volunteer and nominated sampling

audiotape. Twenty-two of the 24 interviews were recorded on audiotape. Second, field notes were made immediately after the interviews. These notes described researchers' perceptions of the interviews and the activities observed. Field notes were also employed in one case where tape recording was technically precluded and once again when an informant preferred not to be taped. Interviews were semistructured and focused on psychosocial perspectives on the current services for renal disease patients and needs for future services.

Data analysis

The interviews were initially recorded on audiotape and then transcribed into a computer, where they were subjected to content and thematic analysis using the Ethnograph 3 program.¹⁴ The field notes underwent similar analysis.

Data were categorized and analyzed at two levels. First, concrete beliefs of the informants were analyzed by examining the words that informants themselves used to describe their experience regarding renal disease: for example, "loneliness," "expense," and "staff training." These words were then considered at a more conceptual level and combined into conceptual themes. Examples of these were "separation," "support," and "quality of care." These code words were derived from theoretical studies that took place before and during data gathering. In this way, concrete data were recorded with simultaneous review of theory.

Content was analyzed by counting the frequency of various themes and ideas in the total body of data. A content analysis provided researchers with some idea of the power of the various themes. Coding reliability was checked through an independent researcher who read all transcriptions. Coding validity was assessed using member checking techniques with three of the original informants.¹⁵ Validity was further enhanced by presenting interview findings to the informants themselves, who judged the summation of

interview material as accurate and representative of previously expressed views. This is a particularly strong method of increasing the validity of study findings and is perhaps the best guarantee of legitimate interpretation of the original representations.

RESULTS

The findings can be described as perspectives on current services for renal disease patients and needs for future renal disease services.

Informants spoke from their personal experiences. However, hypothetical views were shared, for example, when dialysis patients speculated about the possibility of transplantation, family members imagined alternative health care delivery for their ill relatives, and professionals and community leaders expressed their views on issues surrounding the potential satellite dialysis unit.

Perspectives on current services

Informal caregivers and both categories of patients expressed concern over the present system of renal dialysis service. Major criticisms of the present system that necessitates relocation to urban centres included inadequate social support, inconvenience and expense of actual physical relocation, and family separation: "Things that I would normally do at home I couldn't do because she wasn't there, so it was almost like half my life was gone."

It kind of scares you, you know, because the doctors are talking to you. Well, you know people have to move to be near a centre and – good God, you have lived here all your life; we've been here 30-odd years – you don't just pick-up-and-go just like that! It's just not something that you can; it's not an option that you want.

Informants were concerned not only with the actual renal dialysis services per se, but also with problems inherent in any geographical relocation. They expressed concern about

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the inadequacies of facilities in the urban relocation centre. Some informants, including professionals and community spokespersons, expressed concern over language and cultural issues. An environment different from what they were used to, especially if they were not fluent in English, was often reported to be a "scary feeling." Other informants emphasized having insufficient information about their disease and prognosis and receiving inadequate housing. In one urban residence accommodating renal disease patients from MFZ, there are only two bedrooms on the ground floor. Informants expressed a need for more ground floor rooms to improve accessibility for elders and people in wheelchairs. Furthermore, informants reported feeling "out of place" there.

You can't use the facilities when you want to, only at certain times. [T]he last time I was down there, I was there for 1 month, and I was asked to move from one room to another three times. One time I had to visit my wife. They had to put four of us in the room;... that's how crowded it is at times.

Professional caregivers and community spokespersons essentially echoed patient and family concerns regarding the adverse affects of separation from family, lack of social support, and financial burden. They expressed more concern over the potential renal dialysis unit than other informants.

Needs for future services

It is important to recognize that patients will still be relocated even if satellite dialysis services are developed. Some individuals in more isolated communities will need to travel to Moose Factory; therefore, those individuals and their families will experience similar psychosocial disruptions. Several informants identified this concern. All informal caregivers and both categories of patients supported in principle a proposed satellite dialysis unit in Moose Factory.

A dialysis treatment centre established locally was generally seen to address most of the informants'

concerns about the present system; however, three informants still considered housing to be a potential problem. These informants were from outlying areas in the MFZ and were concerned about accommodation and its expense, even though relocation to Moose Factory General Hospital would be considerably closer than the 2.5-hour flight and considerably cheaper than the fare to the present urban centre. Construction of new homes is very slow in Moose Factory, and frequently there are waiting lists; furthermore, patients who have a different band number would be entitled to a house only where their band originated.

Two informants were sceptical of the hospital's ability to provide good quality medical and technical care, especially during the initial program implementation. There was uncertainty whether the MFZ had sufficient numbers of people requiring dialysis to justify this service locally. Still, the benefits of the local unit were clearly acknowledged: "If it ever happens to have that machine in here it would feel more like home - like everybody knows everybody and doesn't feel like it's been a strange place." "It will meet the needs of the people and also cause less problems in the area of homesickness and telephone bills;... sometimes people on dialysis just give up."

Professional caregivers, while generally favouring the proposed satellite dialysis unit, shared the same concern over procedural competency. Training and continuity of care were priorities for this group. Overall, they believed psychosocial and cultural components of care would be more readily recognized with a local dialysis unit. These informants were also concerned about the role of health promotion initiatives in the context of preventing renal disease and, thus, future dialysis need. "We have in excess of 300 people here. They are all geared toward treatment in the hospital, right down from the cleaner to the hospital administrator," explained one informant, who went on

to say that only nine staff people are geared toward prevention.

Looking at health care is more than just symptoms, sickness [as] day-to-day occurrences and responding to it as it arises. There is more to it than that: the quality of living, the housing conditions, the quality of water. All these things.... [J]ust make sure whatever is done is done with that view in mind.

Even if you fish, you get thrown in jail anywhere across the country. Because of the trapping with the animal rights thing, that trapping is not the thing to do. You remain inactive. I think that is probably the reasons for a lot of the change in lifestyle, but it hasn't affected the eating habits and the activities.

We should have more of these people.... They also need to put in a strong home care program, public health education system;... there needs to be more of this.... We need more people, even some of our own people educated to go and educate the people in their own language.

Community spokespersons generally supported establishing a local satellite dialysis unit, but only if quality of care (as defined by biomedical, psychosocial, and cultural terms) could be ensured.

DISCUSSION

Community development context

Despite the quality of the present health care delivery system, perhaps its greatest deficiency is lack of consumer input from Natives themselves. In the past, service planning has been criticized for lacking Native participation in the planning, implementation, and evaluation of services; instead, decisions have been based on federal government goals and objectives.¹¹ Until recently, there has been little collaboration with local communities in establishing a health care system responsive to their needs.

The general trend in health service planning is to gain consumer input. With the recent emphasis on transfer of responsibility from the federal to band level, this trend is being realized in isolated Native communities where health services are delivered by Native boards of health.¹⁶

This alternative approach to improving health is that of local Native community control and development. It is Native people themselves who must analyze the risks and benefits of continuing their traditional way of life in isolated areas and must decide what type of health care personnel they want for their communities, what level of training they need, and what services they offer. Development of Native boards of health is beginning to occur in order to increase Native involvement in their own health and thereby improve the level of Native health.^{17,18} In the United States, alcohol treatment programs that had previously been administered by the national government are now being transferred to the Indian Health Service. The decisive role played by the Native communities themselves is largely responsible for the success this program has experienced.¹⁹

Another issue was the preference for a nearby secondary care centre (Timmins) over the currently used tertiary care referral centre (Kingston) for renal dialysis services. The nearby secondary centre has a population with a larger percentage of Native patients; more relatives and friends of patients reside there. The social and family support was thus perceived by informants to be potentially greater in Timmins than in Kingston, notwithstanding the fact that no informants commented negatively about the quality of care they had received in Kingston. In fact several informants were very pleased with the technical expertise and medical assistance they had received. Most negative comments about relocation to Kingston described homesickness and family separation.

Even so, Native health care must not be discussed in isolation. Economic, political, and social development of Native communities must accompany the discussion so that better housing, a safe water supply and sewage disposal system, recreational facilities for children, and employment opportunities for adults are also addressed. This move toward transfer

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of responsibility for health care is one of the reasons for doing this study.

Implications of study

In principle, a proposed satellite dialysis unit in Moose Factory was supported by all categories of informants and was generally seen to address most of the informants' concerns about the present system. Nevertheless, several issues arise from this study that warrant consideration.

First, there are indications that Native consumers would not be confident in the dialysis skills of the local medical staff because of what they believe could be insufficient numbers of dialysis patients. All categories of informants identified this concern. Therefore, if consumers do not trust the medical staff, they will not use the satellite dialysis services. This is particularly critical in the case of ESRD, where refusal of dialysis results in a life-threatening emergency. Furthermore, professionals could be unavailable or be hesitant to provide a high-tech medical service without a guarantee of expert backup specialists and resources, continuing staff education, and increased public education and community health support.

Second, it is clear that supplementary services, such as housing and community education, are necessary for successful implementation and maintenance of dialysis services, irrespective of the geographic location of such services.

Methodological issues

Qualitative studies of a cross-cultural nature, such as the one undertaken in Moose Factory, have several inherent methodological strengths and limitations. The limitations often prevent such research from occurring in the first place, or they can so adversely affect the study that determining the implications of study findings is difficult if not impossible.

Several methodological limitations of importance arose during this study that are common to other cross-cultural

studies of this kind. First, the interviews were conducted by non-Natives. An interview in this cross-cultural setting that involves direct questions can be perceived as coercive or interfering.²⁰ The second issue, related to the first, is that Native cultures often have health and illness beliefs different from Canadians as a whole. Researchers' interpretations of the meaning of ESRD for individuals can thus be incomplete. Third, the reputational sampling techniques we used could have excluded informants who were happily relocated to a tertiary care setting, who were sicker, or who held views not accepted by the community as a whole.

This type of study has methodological strengths, as well. First, the project was initiated by those studied. The study population believed in the importance of the research; therefore, informants participated in and were committed to the research at all phases. In Moose Factory, and other small communities, commitment on the part of several key individuals is particularly critical. The leadership, good will, and openness of two community elders was instrumental in gaining entry to the knowledge held by this community about their own health and perceived future health needs. Without the high public profile of these individuals (which, for those unfamiliar with Native culture, is not culturally the norm) and their continued advocacy, the study might not have been possible.

Conclusions

Natives experience excess mortality and morbidity in many areas; ESRD is one of these. The second phase of this research examined attitudes and perceptions about ESRD by Native patients and their caregivers, thus contributing to plans for culturally appropriate service delivery. It could be appropriate to generalize study findings to non-Native, rural areas as well. Family separation and increased financial expense are incurred by individuals from isolated communities

relocating for medical intervention. Likewise, professionals in small hospitals share concerns over resources and provision of good quality care. Qualitative studies can contribute to understanding the health needs of smaller communities and assist in considering the distinct needs of these communities in terms of future health planning.

The political will and voice of Natives is increasing and consequently affecting health care delivery. They are beginning to recognize their dependency on a system that has not at all adequately met their health needs.

This hospital and health care in the north available to Indian people and Inuit people has always [chosen to] take them away, and... my attitude to this is:... why should they go to urban centres if they have never been there and if they have no reason to be there and it is only because of this dependency that they have on this dialysis equipment? ■

Acknowledgment

We acknowledge the participation of the Mushkegowuk Tribal Council, the study participants, the staff of the Medical Services Branch at Moose Factory General Hospital, D. Barnes in assisting with data analysis, and C. Lysack in helping to prepare this manuscript.

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