THE IMPACT OF URBAN RELOCATION ON NATIVE KIDNEY TRANSPLANT PATIENTS AND THEIR FAMILIES: A RETROSPECTIVE STUDY

BY

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ABSTRACT

The research, reported within this thesis, was designed to study the impact of urban relocation upon Native Canadian kidney transplant patients and their families through an analysis of clinical and biographical case histories.

Data were derived, primarily, from interviews and participant observation. Interviews with post-transplant patients and where feasible, a family member were focused upon recall of their urban relocation experience as necessitated by their disease. Interviews with representatives of several health care delivery agencies elicited services to and problems of patients with end stage renal disease (ESRD), specially referred to Native ESRD patients and their families. These agencies included: the Manitoba Local Centres Dialysis Program (MLCDP); Medical Services Branch (MSB) their medical boarding homes; Manitoba Social Allowances Program (SAP); and the South East Resource and Development Council (SERDC). Participant Observation was conducted and observations recorded within the transplant clinic environs; the Dialysis Support Group and Dial a Life, a proposed housing project for medically relocated Native individuals.

Qualitative analysis of data supports the conclusion that each Native patient must be viewed as an individual entity rather than a modal representative of the collectivity of Native people. Each patient and their family members have learned to "adjust" to their illness, their treatment, and their relocation, using their own coping skills.

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ABBREVIATIONS

CAP - Continuous Peritoneal Dialysis

CAPD - Continuous Ambulatory Peritoneal Dialysis

CCPD - Continuous Cycling Peritoneal Dialysis

CORR - Canadian Organ Replacement Register

ESRD - End Stage Renal Disease

DNA - Did Not Arrive

HSC - Health Sciences Centre

IPD - Intermittent Peritoneal Dialysis

MIP - Medical Interpreters Program

MLCDP - Manitoba Local Centres Dialysis Program

MSU - Midstream Urine

MSB - Medical Services Branch - Health and Welfare Canada

NIDDM - Non-insulin-dependant-diabetes mellitus

OKT 3 - Orthoclone (Immunosuppressive)

SAP - Social Allowances Program

SERDC - South East Resource Development Council

SBGH - St Boniface General Hospital

CHAPTER I: INTRODUCTION

End Stage Renal Disease (ESRD) is the final result of a progressive loss of kidney function. This condition is irreversible and permanent. Dialysis (three times a week, four to five hours a treatment) or kidney transplantation are necessary to sustain the patient's life.

The objective of the research, detailed herein, was to study the impact of urban relocation upon Native Canadian kidney transplant patients and their families through an analysis of clinical and biographical case histories.

EPIDEMIOLOGY AND NATURAL HISTORY OF ESRD:

ESRD derives from several different causes, including one or more of: (1) those that directly affect the kidney by infection, inflammation and upper urinary tract infection; (2) those in which there is an obstruction in the lower urinary tract; and (3) systemic conditions and toxicities, eg. hypokalemia, hypercalcemia, hypertension, disseminated lupus erythematosus, atheroma, diabetes mellitus, heart failure, and cirrhosis of the liver (Miller 1983). Metabolic/physiologic disturbances resulting from each of these also produce concomitant effects, complex and profound, on the function of extra-renal organs and organ systems (Eknoyan 1984).

Early predictors of ESRD can be ascertained through biochemical assessment, such as: blood and urine tests and through radiography and tomography (Stone 1982; Eknoyan 1984; Whitworth 1987).

PREVALENCE/INCIDENCE OF ESRD: The main Canadian repository for current data pertaining to ESRD is found in the Canadian Organ Replacement Register (CORR 1988). Previously, the data were presented in the Canadian Renal Failure Register. Both reports have been published by the Kidney Foundation of Canada. Time and experience have resulted in changes to the data collection format, and to the organization of reports, as manifested in the most recent publication. For example, in the 1987 publication, the database was expanded to incorporate non-renal solid transplants, while maintaining the previous renal transplant database. The volume of data collected for transplanted organs was increased by using a modular system and data entry was also made more efficient. The report also contains aggregated data on all patients and also on registered patients (patients by age and gender who began treatment for ESRD since 1981). In general, data from the previous years have been duplicated. The current (1988) report has attempted ... "to verify the information on the existing database and this has resulted in a number of modifications to the patient specific data". Thus, in the 1988 report ..."some of the figures will differ from previously published reports" (CORR 1987:iv). The 1988 Canadian Organ Replacement Register reports 10,401 registered patients of which 1,929 were new patients. In the 1987 CORR there were 9,310 including 1,826 new patients (CORR 1988:5). There are now more individuals alive with a functioning renal transplant (5,208) than there are in the total numbers of individuals on dialysis (5,193) (CORR 1988:5).

CONCOMITANT/SYNCHRONOUS EFFECTS OF ESRD: Macrovascular disease is a primary cause of death in non-insulin-dependent diabetes (NIDDM) and cardiac

diseases are the predominant causes of death (344/947 or 36.3%) in registered Canadian ESRD patients; 10.2% (N=97) of total deaths are due to infection; 7.4% (N=70) to vascular diseases and 15.5% (N=144) to "social causes" (which include refusal of further treatment or suicide). All statistics are the highest in the 65+ age group (CORR 1988:60-61). Silins et al, 1989, using the Canadian Renal Failure Register (1986), reported that the mortality rates of ESRD patients were at least three times higher than those of the general Canadian population.

The synchronous effects of ESRD are many and varied. These are manifested in a number of syndromes which, in and of themselves, pose very serious health problems. Some of these effects have been noted since the inception of the Renal Failure Register in 1981 such as an incremental rise in the number of diabetic patients with ESRD. Currently

> Two thousand three hundred and thirteen diabetics have been registered from January 1, 1981 to December 31, 1988 and represent 18.9% of all registered patients. The number of diabetics has risen from 191 (8 per million of the population) in 1981 to 431 (17 per million population) in 1988. Diabetes was the primary diagnosis in 22.3% of the new patients in 1988. There was considerable interprovincial variation ranging from 12.5% of new patients in Newfoundland to approximately 30% in Manitoba and Saskatchewan (CORR 1988:36).

Diabetes has replaced glomerulonephritis as the primary determinant of chronic renal failure in Canada, accounting for 431 new patients of all ages compared to glomerulonephritis at 406. Renal vascular disease accounted for 269 new patients. In patients 65 years and over (N=591), renal vascular disease accounted for 161 new patients. The treatment modalities of haemodialysis and peritoneal dialysis account

for 147/339 and 192/339 respectively for new diabetic patients with ESRD (CORR 1988:58). There are 26/431 new diabetic patients who are alive with a functioning transplant. (CORR, 1988:58)

Silins, et al (1989), using the 1986 data reports that there were significant differences in the probability of dying from ESRD between those patients with and without diabetes mellitus. Diabetic patients had a Standard Mortality Ratio (SMR) twice as high as that of nondiabetic patients. It is noted by the authors that the estimate for the diabetic group contained the effect of both the ESRD and the diabetic condition. This could be corrected, as the authors suggest, by using a diabetic group free of ESRD - a more comparable situation would therefore develop.

The incidence of ESRD in patients with diabetes mellitus is reported to be higher in some populations than in others. Cowie, et al (1989), using a Michigan study which was conducted between 1974-1983), suggest that ..."the incidence of diabetic ESRD was 2.6-fold higher (P less than or equal to 0.0001) among blacks" after the authors had adjusted for the higher prevalence of diabetes among blacks, with the excess occurring predominantly among blacks with non-insulin- dependant-diabetes (NIDDM).

Silins et al (1989) also suggest that there are significant differences in the probability of dying from ESRD between whites and nonwhites.

ESRD IN NATIVE NORTH AMERICANS:

Diabetic nephropathy, a phenotypic amplification of NIDDM, has been implicated in ESRD among the Pima, Zuni, and Navajo (Nelson et al 1988; Pasinski et al 1987 and Megill et al 1988). The Pima Indians of Arizona and the Zuni of western New Mexico are populations with high prevalences of NIDDM (Nelson et al 1988). "Diabetic nephropathy accounted for 50% of all new cases in 1985, with an incidence 9.6 times that in US whites, and was due entirely to type II disease" (Megill et al 1988: 178).

The early 1960's literature pertaining to Native diabetics, suggested that a ..."special Indian" diabetes existed, presumably devoid of the complications of blindness, renal failure, amputation, and acidotic coma," although one study did mentioned indications of early retinal changes, kidney function decrease etc. (Justice 1989:50). However, as this first diabetic generation aged and were not able to maintain a normal blood sugar through the use of diet and drug therapy, secondary complications emerged. It is now believed that at the time of these early studies, overt diabetes had existed less than 15 years, therefore not providing enough time for the diabetic complications to occur.

> Mothers with high uncontrollable diabetes during pregnacy gave birth to the next generation, the children they gave birth to became obese at younger ages, were at risk for developing diabetes, and developed this disease at a younger age than did their parents (Justice, 1989: 50).

Nondiabetic ESRD is also reported among the Navajo Indians. Smith et al, hypothesize that mesangiopathic glomerulonephritis ..."is probably responsible for the high rates of nondiabetic end-stage renal disease seen in the Navajo Indians" (Smith et al 1989:158). This is also the case for the Zuni (Hughson et al 1989). Nevertheless, diabetes accounts for 50% of the cases reported by Smith et al (1989) and 24% (diabetic nephropathy) by Pasinski et al (1987) among the Zuni.

Recent studies, conducted to determine the prevalence of non-insulin-dependent diabetes mellitus (NIDDM) among Native Canadians (Young et al 1987), attest to the fact that this syndrome is a major health problem. Given the association of ESRD and diabetes mellitus, it can be expected that many individuals among the Canadian Native diabetic population will progress to this terminal state as is apparent with their American counterparts.

Research upon the Canadian Renal Failure Register (1986) has indicated that Canadian Natives are at a much higher risk for ESRD than the Canadian population in general. The authors of the study used "...two population estimates for the total Native population," and discovered "the age standardized incidence rate of newly registered ESRD cases between 1981 and 1986 among Natives was at least 2.5 times (and may be as high as four times) the national rate" (Young et al 1989:756). Using hospital admission data for patients with genito-urinary disease, John McKenzie reports that there are over twice as many Native Manitobans admitted to hospital as there are for all Manitobans on an age standardized basis. "Under nephritis, nephrotic

syndrome and nephrosis, the Native Manitoban rate is 3 1/2 times that of the general rate" (McKenzie 1987:5).

Linkages of streptococcal infections to chronic nephritis represent another synchronous effect of ESRD. There are several arguments as to the long-term effects of this condition. A ten year follow-up study of a Minnesota Ojibwa population with a high incidence of streptococcal disease

> in which endemic glomerulonephritis is not uncommon demonstrated that chronic progressive renal disease has not occurred in 100% of the 61 individuals who had acute poststreptococcal glomerulonephritis ten years previously, despite exposure to recurrent streptococcal infection" (Perlman 1965:175).

Whitworth, suggests that other studies report that up to 10% of patients with acute diffuse exudative proliferative glomerulonephritis ...."will, within 20 years of recovery from the acute illness, develop chronic renal failure." Proteinuria usually continues for more than 5 years after the acute disease in 25% of adults and 5-10% of children. Whitworth continues by stating that: "The consensus is that chronic renal failure is very rare (1-2%) following childhood disease and uncommon (around 5%) in adults" (Whitworth 1987:115). It is also noted that this condition has declined dramatically in developed countries due to improved nutrition, hygiene and the use of antibiotics. Dr. John K. McKenzie (1987) believes that we must know the kinds and determinants of renal disease from which Native Canadians suffer. One important question is the relationship to poststreptococcal glomerulonephritis, common on the Reserves, which is usually related to skin infections.

RELATED HEALTH AND SOCIAL CONDITIONS: The health and social conditions of Native Canadians are not comparable to the Canadian population in general. Conditions which are attributed to underdeveloped countries are paralleled and documented in the Canadian Native population. Peter Sarsfield, (1988:122) in addressing the health issues in northern Canada suggests:

> In northern communities, still-births, perinatal death rates and death of children under one year of age are over twice the national average. Death from violent causes, including accidents, suicides and murders, are ten times higher for indigenous northerners under age 25 than for the rest of the country. The life expectancy of an indigenous newborn is 20 years less than it would be if the infant were born in urban southern Canada. Social conditions parallel the grim health statistics. People living in cold, crowded, poorly-built housing, more often than not without proper provision for sewage or garbage disposal, and often with only contaminated water to drink.

Alcoholism and drug abuse play a large role in these health and social statistics and due to their toxic effects contribute to the concomitant consequences of ESRD. In a general sense, alcohol-related problems are a major social and health issue in our society. According to Canada Year Book (1990:3-8)

> The number of cases separated in 1984-85 from psychiatric hospitals and general hospitals with a primary diagnosis of alcohol dependence syndrome and alcoholic psychoses was 24,361 and accounted for 570,342 patient days. In 1972, there were 35,326 separations reported utilizing 794,891 patient days. Of the separations in 1984-85, 88% were male and 12% were female with a median age of 47 and 45, respectively.

Alcohol abuse is cited to be widespread among northern Native individuals (Postl 1989). Sarsfield suggests that in Northern Canada; "We have "progressed" from TB and starvation to suicide and malnutrition, from dehydration to drug abuse, and from dependency to self-destruction" (Sarsfield 1988:122).

Jarvis and Boldt (1982:1327) writing on the death styles of Alberta's Native population suggest that two chronic conditions by which Natives experience a ..."a higher proportion (5.8%) of deaths are cirrhosis and alcoholism. These causes bring about only 2.3% of deaths in the general population". They also believe that alcohol is directly and/or indirectly related to the deaths of their study group. "That is, 4 out of 5 of the 52.8% of deaths not due to natural causes are in fact directly or indirectly attributable to alcohol abuse" (Jarvis and Boldt 1982:1349) As well, the term "natural causes" may mask the antecedent or secondary cause of death therefore confounding the interpretation of the statistics.

Romanowski and Schaefer (1981) report that among Natives in Charles Camsell Hospital in Edmonton, Alberta, from 1950-80 there was an unusually high frequency of alcoholic liver cirrhosis for Native females. Mao et al, 1986, using age specific and adjusted mortality rates for the years 1977 -1982 state that the standard mortality ratio, (SMR), was greater than 3.0 for Native Canadian women for cirrhosis/alcholism.

DEMOGRAPHY: The 1986 census, reports 374,200 registered Indians in Canada or 1.5 % of the total Canadian population. Registered Indians constituted 64% of Canadas total Native population as of 1981. As of 1982, about one-third of Indian bands were geographically classified by Indian and Northern Affairs Canada (INAC) as urban and the rest as rural, remote or requiring special access. Nearly one-quarter of the on-reserve population were in remote or special access zones (Lithwick 1986). Manitoba has the highest proportion of its band population living in remote or special

access areas. The proportion of Manitoba's band population living in INAC urban areas was the lowest of any region (Hull 1987). The Manitoba Native age structure was also much younger than the general Manitoba population (44% of Natives below age 15 in 1981 compared to 23% of the total population).

"The Registered Indian population was younger than the reference population, according to adjusted Register data. For example, in 1981, 62 per cent of all registered Indians, compared with 42 per cent of the reference population, were under 25 years of age" (Lithwick 1986:3). The registered Indian population was expected to maintain its relative youth through to 1991, with an expected higher median age. This report suggests that as a result of this youthfulness, the registered Indian population had, and is expected to continue to experience, higher dependency ratios (0-15yrs) than the total Canadian population. The growth rate (1971-1981) for the registered Indian population was higher than the Canadian population as a whole and was expected to remain the same for the rest of 1980's.

As noted in the Age-Sex profile for the total registered Native population (on and off reserve) (Graham 1987), the population pyramid is changing from a truncated appearance, (where there are few individuals in the older age cohorts) indicating higher levels of mortality at younger ages, to one consistent with lower levels of mortality and an ageing population. If the mortality levels drop, a larger proportion of those Native individuals who are born survive to the age groups were they are at risk for chronic diseases. Therefore, ..."as survivorship by age and gender increases, the risk of chronic disease also increases" (Rokala Personal Communication 1990). A continuing increase

in the numbers of patients with age-related conditions, such as non-insulin dependant diabetes, diabetic nephropathy, and ESRD will be of the utmost concern to our health care system.

At present, the Canadian Native non-age specific risk factors data show relatively low prevalence rates for diabetes mellitus in linguistic and geographic groups even though it exceeds the age adjusted non-Native prevalance statistics. On demographic bases alone, it can be expected that the prevalence for these groups will be increased substantially, given the present numbers of Natives with diabetes as a primary disease whose terminal disease will probably be ESRD.

The effects on the health care system and the future health status of Native Canadians is of outstanding significance given: a) its youthful population; b) the expanding numbers of individuals within that population; and c) the increase in the incidence and prevalence of individuals with ESRD interacting with the inherent risks of diabetes, streptococcal infections, alcoholism and drug abuse.

RESIDENTIAL RELOCATION AND ESRD:

Moving or relocating from one's home environment is one of life's stressful experiences. For the individual with ESRD the stress produced by residential change is compounded by the fact that they must enter a foreign and powerful medical environment. For the Native individual with ESRD these issues are amplified by the fact that relocation means having to adjust to language, cultural and economic differences as well.

HISTORICAL ASPECTS: Relocation is not new to the Native people. Initiation of the reserve system saw the Natives uprooted from their traditional way of life and placed on land "reserved" for them by the government. Federally funded economic programs required Natives to move to large centres, such as reported in the study conducted on relocated American Indians in the San Francisco Bay area (Ablon 1964) and the forced Navajo relocation due to tribal differences with the Hopi (Thayer 1982). Bureaucratic centralization was and continues to be another motive for the relocation of Canada's northern people (Brody 1974) as was the centralization of the educational system. In order for this latter process to occur, children were taken from their home communities and placed in boarding schools within the southern areas of the country.

Diane Durin (Unpublished) wrote of her tenure as a teacher in the Chipewyan and Cree community of Brochet, Manitoba and discussed the fears of the Native parents sending their children to the "outside world" for their schooling. During Miss Durins' time in Brochet (1969-70), two daughters from the same family who were sent to The Pas, Manitoba for their education were struck with tragedy. One was murdered, the other raped and returned to her community to have her illegitimate child. Experiences, such as these, created for the Native people, an environment of distrust and wariness of the "outside" world.

The reasoning behind the relocation plans may not always have been altruistic. Governmental agencies stated they wanted to improve and to centralize economic and training facilities along with improving the delivery of governmental services. What

did ensue, in some cases was racial, economic, and social difficulties for the Native peoples.

Lorraine Brandson (1981) writing about the move "From Tundra To Forest" of the Chipewyan or "Dene" from Duck Lake to Churchill, Manitoba stated that social problems resulted, such as: ill health, child neglect, criminality, alcohol abuse and vandalism.

Historically, northern Native people were moved to the south for medical therapy as occurred during the tuberculosis epidemics in the mid-point of this century (Hodgson 1982; Young 1979). There are still Native individuals who can remember relatives and friends being removed from their communities to be placed in a southern hospital and that some of these patients were never to be heard from again.

Another viewpoint is presented by Jacques Grondin, writing of the removal of the Inuit to southern medical centers. He suggests, that in order to understand the problem, one must comprehend the interrelationship of three explanatory levels; the macrosocial level, which explains the geopolitics of health, the mesosocial level, (community dynamics), and the microsocial level, (personal and family histories). He is not suggesting that there are no inherent problems resulting from the act of relocation, but rather that researchers should look at some of the ways that the Inuit, for example, adjust themselves to the Eurocanadian health care system using these three hierarchical levels. Grondin also believes that one should not use the ethnicity argu-

ment as the reason for relocation difficulties. He postulates that..."the Inuit are reacting to and confronting the problems just as anybody, anywhere" (Grondin 1989: 35-36).

STUDIES ON THE EFFECTS OF RELOCATION: As is noted in O'Neil et al (1988) and P.Kaufert et al (1988) there has been a change in the place of delivery of Inuit infants from their northern home communities to larger treatment centres in the south. As a result, women are evacuated, in some instances, removing the pregnant mother from her home community anywhere from two weeks to two months before her delivery time. As a result of this evacuation the women complain of "loneliness, boredom, anxiety and fear" (O'Neil et al 1988:87). These authors also find that there are definite relocation effects on the health and stability of the families of these mothers. Women must leave their husbands and other children in the care of family members where, in some cases, they may not be accepted as part of the family. The husbands may not be proficient in the care of young children and the added demands on their time has driven some husbands to call their wives in the southern hospitals and insist that they return home. When the woman is the wage earner -the loss of her salary if she is on unpaid maternity leave, can have a major impact on the family finances. If the husband has a trap-line and must care for his children - he is unable to leave the home to check on his line or repair his equipment - taking the children with him would be dangerous given the environments to which they would be exposed.

The problems associated with the short-term removal of Native individuals from their home communities have been shown to be substantial. Hence, over the long-term,