

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

**BY
C. JOAN MOLLINS**

**A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements for the Degree of**

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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 (Eknayan 1984).

Early predictors of ESRD can be ascertained through biochemical assessment, such as: blood and urine tests and through radiography and tomography (Stone 1982; Eknayan 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 pregnancy 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 prevalence 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,

the difficulties experienced by the chronic ESRD Native individuals would be expected to be amplified.

Some studies have been conducted on relocation in areas of potential relevance to delivery of medical care. Kathryn Puskar (1986) uses Mahler's Phases as a theoretical framework in order to understand relocation. Mahler's Phases were identified as developmental areas of separation in nursery school-age children. She suggests that these stages may be analogized and operationalized to women who must relocate. The study, using home interviews, and six in-depth case studies suggests that a woman's previous experience with separation will influence the degree and amount of anxiety, depression and coping strategies that she will employ in her relocated position. This study does not relate the reasons behind the relocation other than for a change in the husband's employment. In summary, however, the author hoped that the phases could be used by maternal-child health nurses and psychiatric-mental health nurses to better understand how patients cope with separation.

Relocation has also been studied relative to its effects on the elderly (Dimond et al 1987) and on the adjustment to relocation of long-stay psychiatric patients (Hills 1987). Both studies suggest that relocation did not appear to affect the older patients but that support groups were an integral part of this adaptive process. Some symptoms, attributed to involuntary relocation for the elderly patients, were those of grief ... "decreased health, self-esteem, and mood, and with increased worry and sense of alienation" (Dimond et al 1987:458). The authors also believe that relocation is a

process and not just one event in time and the event does not affect all the subjects in the same manner.

The economic costs of medically treating patients are very high. As was noted earlier in this presentation, demographically a large portion of the Native population in Canada and Manitoba live outside the major population centers and in many instances reside in remote areas of the province. Therefore, access to medical treatment centres can be problematic.

Relocation is in some instances necessary. In the case of disease or illness which requires the services of expensive, technically sophisticated equipment, e.g. cardiac units, individuals must travel to the unit in order to seek diagnosis and/or treatment.

It has been noted that for the new dialysis treatment centre to be established in the Thompson, Manitoba hospital, the provincial government has allocated \$25,000 to purchase the dialysis machine and another \$100,000 annually in operational costs (Wpg Free Press, Sept. 6/89:9). As a result of this expense, dialysis units must draw on a larger, regional population in order to make full use of its facilities.

In Manitoba, there are presently six kidney dialysis treatment centres. These are in the communities of Winnipeg, Brandon, Morden, Dauphin, Flin Flon, The Pas, and Thompson (Wpg. Free Press, Sept.6,1989:9).

STUDIES SPECIFIC TO ESRD: In studies of relocation specific to ESRD, the advantages of one dialysis mode over the other, e.g. peritoneal (conducted in a

treatment setting, possibly in another community) vis-a-vis hemodialysis (conducted in the home) are evaluated (Blagg 1970). Studies such as this stress the availability of the treatment facility, mortality/morbidity associated with the complications of the disease, psychologic problems and the patient's impending rehabilitation.

Abram uses case studies to show the psychiatric aspects associated with "uprooting" families in order to be near the dialysis units. One patient explained that "he didn't think he wanted to leave home, his familiar surroundings, and his work" in order to have either dialysis and/or transplantation (Abram 1968:1356).

ESRD patients living in remote areas are often faced with inadequate water supply, overcrowding and lack of aseptic conditions, serious impediments to the conduct of their treatment within the home environment. In some instances not only must northern ESRD patients move to the larger treatment centres, e.g. Winnipeg, because of the availability of the technical facilities, but the family members must also uproot themselves. This removal from their home communities from jobs, familiar surroundings and from families, may have profound implications on the ESRD patient and on the family itself.

Don Enman states their problems succinctly.

For Native people, particularly those who reside in remote communities and reserves, these issues "(medical, employment, and transportation)" are magnified. Diabetes and renal disease often affect multiple members of the same family. Nephrology specialists and dialysis and transplant programs are only located in larger population centres. Diagnosis, treatment and ongoing medical management is inconvenient and disruptive. Transportation becomes involved and even unreliable in certain seasons. Accommodation and transportation must be arranged in the centres where treatment is provided. Many natives with

chronic renal failure must relocate to major centres for indefinite periods. Their future is often uncertain. Difficult decisions must be made whether to locate families or allow families to be split. Housing, employment, finances, transportation, socialization, and recreation must be dealt with in an alien environment. Cultural differences, language barriers, and racial discrimination make adjustments very difficult for many. (Enman 1988:2)

It is therefore evident that there are many hidden human dimensions within the act of relocation. The researcher must be cognizant of the fact that there are confounding conditions involved in the act of relocation. One must attempt to separate the variables which result from relocation pertaining to a medical condition, e.g. ESRD, and the act of relocation itself. These two seemingly distinctive conditions may work synergistically with social, economic and political conditions to create a larger and more complex problem for Native ESRD patients and their families. By adding the process of relocation and the apparent problems related to the prevalence/incidence of ESRD, one is able to comprehend the growing importance and magnitude of the issues facing the health care system and the Native communities.

The chronic nature of ESRD has a greater social and economic impact on the individual as well as ..." being responsible for an increase in the number of premature deaths, morbidity and disability in society" (Balram 1989:42).

How individuals react and cope either positively and/or negatively to their condition has been examined by numerous authors. For example, Christopher Blodgett in his review of the literature on adjustment to hemodialysis suggests that the implications of this body of information moves beyond the patient group with ESRD to include patient groups with other chronic illnesses. Among others, these include adjustment to

terminal illness, tolerance of intrusive medical procedures, establishment of therapeutic alliances with the treatment staff, redefinition of family relationships, and the ordering of life goals (Blodgett 1981-82:97).

Coping, either viewed as a positive or negative mechanism, as in other chronic diseases, can be a form of denial. For example, when an ESRD patient observes negative instances with their treatment, which may reoccur, the problem may be viewed by the patient in the singular situation - they thereby cope with the present problem rather than focusing on the fact that in the future the problem may be repeated.

The psycho-social aspects of ESRD (Abram 1970) focus on the stresses, losses and the restrictions which are imposed on the patient, his/her family and other caretakers. The psychiatric reactions, such as, the role that dependant/independent behavior plays in the disease, the use of denial (a major defense mechanism), alterations in the body image, and attitudes towards life and death, are all discussed in terms of psychological reactions to the stress of hemodialysis. Suicide, both active and passive, and the moral, ethical and economic problems of patient selection as to whom receives the expensive renal treatment are also considered. The author uses the patients thoughts and fantasies to develop a subjective record of these psychiatric reactions.

Quality of Life is another variable often researched and recorded in the literature. Beard (1971) reports upon the quality of life before and after renal transplantation. He postulates that quality of life can only be determined subjectively by the individual. The researcher can make certain judgements about ones quality of life by

comparing certain criteria in the patients life with that from a previous time. These criteria, Beard suggests, are indicated by the ESRD patient. Parameters include,

... self-worth, self-image, the nature of relationships with significant others, value judgements as to what is important in life, and areas of active involvement with the environment (Beard 1971:24).

Beard also suggests that the family is explicitly linked in the renal transplantation process.

Parenthetically, experience is beginning to teach us that the patients who adjust the best are those who have a concerned, supporting , and stable family, and have a deep and meaningful relationship with at least one significant member of that family (Beard 1971:25).

In the seminal article, "Ernie Crowfeather", (Fox et al 1978), the cultural perceptions of the native ESRD patient, his family and the staff of individuals assigned to his care are shown to be problematic. The medical ethics of when to begin and discontinue Crowfeathers' life saving treatment becomes an issue. It appears that he does not wish to comply to the suggested mode of treatment and is thought not to be a "contributing member of society". The family is placed in a difficult position as they are usually relied upon to reinforce in the patient the implied importance of the medical regime. Other factors must be considered by the medical personnel in order to arrive at an understanding of the decisions made by both the patient and his family. The dilemma of scarce resources and relocation to a treatment centre must also be addressed.

There are various levels of meaning given to the treatment of the ESRD patient.

The treatment of ESRD involves a very elaborate medical ritual that generates multiple levels of meaning through a variety of public and private experiences with the technologies of dialysis and transplantation (Plough 1987:12).

These levels of experience include the individual with the kidney failure, the family, the medical care providers who treat the patient, the clinical researchers, the Federal bureaucrats, the private medical firms who manufacture, sell and service the equipment used by the ERSD patient and the publics' understanding of the ESRD condition. There is little research which focuses on how the patient fits into this social network, instead the Clinical - Medical Model takes precedence. This model addresses issues in a quantitative manner, such as measuring survival, and the cost-benefit of a certain technology.

This form of technology assessment will, as a general rule, ignore the hidden dimensions of contradiction and conflict in the variety of experiences that people have with medical technology (Plough,1987: 5).

In focusing upon these hidden dimensions, rather than the medical aspects of the disease, it is crucial to realize that family in the broadest sense is very important to the Native people and when separated it takes on a special meaning. The following comment is recorded from research on family systems approaches for treatment of Natives with alcohol and drug abuse.

Although family is physically separated by distance, it still maintains close ties. A mothers' responsibility to her children is for life. It is her responsibility to keep everyone in close contact and to teach the eldest daughter to continue this tradition (The Bulletin 1988:5).

PURPOSE:

Review of the literature has indicated that ESRD has many interrelated facets. These include the combination of the following impacts: physiological, psycho-social, economical and cultural. These interact to varying degrees upon both the patient and the family. In order to examine the extent of these impacts, the researcher has undertaken a multifaceted approach. This included:

- a) interviewing post-transplant patients and, where feasible, a family member, regarding their recollections pertaining to their urban relocation which was necessitated by their dialysis treatments.
- b) interviewing representatives within several health care delivery agencies who offer services to ESRD patients and specifically to Native ESRD patients and their families. These agencies include: the Manitoba Local Centres Dialysis Program, MLCDP; Medical Services Branch-Health and Welfare Canada, MSB and their medical boarding homes; Manitoba Social Allowance 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 Dialalife. MSB and their medical boarding homes; SERDC; the Dialysis Support Group and Dialalife offer programs which are specific to Native individuals.

The adoption of different roles in this research allowed for further retrospective investigation. This "... obligates the investigator not only to examine the data which are the end product but also to go behind the scenes and evaluate the forces which have channeled the material to his attention, ..." (Mantel & Haenszel 1959: 724).

The researcher presents her thesis by providing the methodology whereby the information was collected. This is followed by stipulating a context from which to understand the previously listed programs and services that a Native ESRD patient / family must interact with on a daily bases. A hypothetical case study is presented, compiled from the results of her own research, along with her experiences as a Senior Research Associate with the ESRD Relocation Impact Study. Using information from both the contextual and hypothetical case study chapters, the researcher interprets her findings and subsequently presents her conclusions.

CHAPTER II: MATERIALS and METHODS

There are 293 individuals who are registered in the Manitoba Renal Transplant Register. Fifty-one individuals (17%) are Native patients from Manitoba and northwestern Ontario, who have undergone kidney transplantation between 1971 and 1990. The largest numbers of Native kidney transplants were performed in 1985, 1988, and 1989, 8, 7, and 8 respectively. (Table 1)

Transplant recipients attend a Transplant Clinic once a week for the first year following transplantation and, subsequently, once a month for the rest of their lives. The Transplant Clinic in Manitoba is held at the Health Sciences Centre in Winnipeg. Some patients, whose conditions are considered stable, may be examined periodically throughout the year in the larger medical centers situated within the province and northwestern Ontario. These patients are all eventually examined at least once a year in the Winnipeg Transplant Clinic. The frequent visits and the close clinical control which are necessary following renal transplant, dictate that the individual must remain in close proximity to the Transplant Clinics. These monthly visits served as the bases for my thesis research.

Transplanted patients and their families were selected for this research because they would necessarily have undergone a period of renal replacement therapy. These individuals have already experienced relocation from their home communities and have developed some coping strategies, either negatively and/or positively in the process. Also these transplanted patients, by the fact that they have received a renal

transplant, will have been screened as to serious and multiple complications as opposed to non -transplant patients. The operating assumption in this research is that there is some degree of impact on the relocated ESRD patient/family. An ethnographic description of this process, its contexts and consequences, is presented and analyzed within the context of patient/family case histories derived from the cohort of transplanted patients from the years 1985 and 1988.

METHODOLOGY:

Initial access to a sampling frame of Native patients with ESRD was derived from Young et al, 1989 who utilized the Canadian National Renal Failure Register to obtain their data ..."that Canadian Natives are at much higher risk for ESRD than the Canadian population in general" (Young et al, 1989:756). The researcher was then introduced to and subsequently obtained study approval from the Head, Section of Nephrology, Health Sciences Centre (HSC); the Director, Transplant Program, HSC; and the nursing staff, Transplant Unit, HSC.

In order to obtain the subject pool for this research, various sources were explored and investigated. These included the patient lists. From the initial patient list collected in the spring of 1990, fifteen (15) Native patients were identified as undergoing transplantation in the years 1985 and 1988 (Figure 1). In the fall of 1990, this number was corrected to eighteen (18) patients. The increase in the number of patients was attributed to an updated patient listing supplied by the Director of the Transplant Program from the National Kidney Disease Registry. The patients in the latter group were coded with the number two (2) for Native "race." Fourteen (14) of these patients

had a treaty number recorded on the information page of their chart. All patients were designated by the Clinic staff as Native through physiognomic characteristics.

When I returned to the Clinic in December 1990, five of the eighteen individuals were removed from this sampling list (Figure 1). Two patients, from this group of five, had been identified in the ($N = 15$) group and the remaining three patients had been added from the updated National Kidney Disease Registry. The reasons for the deletion of these five individuals were: one patient died; one patient was very ill and subsequently died; one patient was under age 18, (necessitating a further ethical approval); one patient only attends the Clinic in the summer months, as they attend school in another province in the winter months; and one patient had "lost their kidney" and returned to dialysis.

The remaining thirteen patients were all approached in the Transplant Clinic and asked if they had to move alone or with family members to Winnipeg when they had to have their dialysis. The term "relocate" was immediately deleted from this question as the first two patients asked to have the word repeated, indicating a failure to understand that particular terminology. From this general statement, these patients all understood the difference of moving to the city, permanently (for the duration of their dialysis treatments and approximately one year post transplant), either alone or with their family as opposed to the temporary nature of living in a medical boarding house and/or a hostel accommodation (in all cases without a family member).

There were no refusals to speak to the researcher either during the initial or subsequent interviews. The later interviews were conducted from one half hour to two and one half hours in duration.

Race, as designated on the local Transplant Unit Register, HSC, consisted of Canadian, Native, Black, Eskimo, Filipino, and Asian. At the present time, the National Register and/or the local register does not furnish detailed criteria on what constitutes racial origin.

The Native individuals were initially identified, as distinguished from non-Native, by a Transplant Clinic nurse. The assignment of these individuals to the Native group is generally through physiognomic characteristics. Review of the information sheet on the patient's chart resulted in the recovery of 41/51 Band Numbers indicative of Treaty Indian Status. Validation of the identified Natives who did not have a recorded treaty number necessitates further investigation. It has been suggested from a previous study, that this would include asking those individuals who do not have a recorded Band Number and who are part of the study group if they have a Treaty Number but it was not recorded. If this procedure does not capture Band Numbers then the patients' charts would have to be examined for notations requesting Native interpretive services; requesting Native transportation, eg. "Thunderbird Transportation"; requesting Native traditional food; and staff notations regarding some aspect of the individuals Native history (Young et al, 1989:756).

Investigation of the local register revealed a lower number of Native transplant patients, 51 (Table 1) as opposed to 57, (corrected to 54) from the nurse supplied listing (Table 1). Three patients were accounted for by death; removal of transplant and the return to dialysis; and attending the (HSC) Transplant Clinic for only the summer months. Transplants that were performed at Transplant Units outside of Manitoba accounted for the remaining three patients. Therefore, Native individuals are treated at the HSC Transplant Clinic who are not included in the local register. The numbers of patients in each of the years, 1985, 1988, and 1989 corresponded between the two lists as did the patients names. A combination of the two records were utilized for this research.

The patients name, address (temporary and/or permanent), phone number, age, primary diagnosis, transplant date and donor were obtained from the information sheet, contained in the patients' chart. Winnipeg was indicated as the current address for 32/51 individuals. The remaining transplant patients resided in various other areas or regions of Manitoba and northwestern Ontario.

As noted earlier, the largest numbers of patients undergoing the transplant procedure occurred in 1985, 1988, and 1989. One patient in 1985 was a retransplant from a 1971 procedure, the former transplant having survived for 13 years.

The concentration of this research was restricted to individuals within two groups, (1985 and 1988). This permitted a measure of control over the potentially confounding effects of early transplant rejection and other post operative complica-

tions. If these patients wished to return to their home community post-operatively, they would have had the opportunity to have done so.

The study groups have 7 males and 8 females within the age range of 27 to 67 years. (Table 2).

Further attrition from this group of 15 individuals was anticipated. The following factors, at least, weighed heavily in the determination of final study group size.

- a) Two individuals attended medical facilities outside of Winnipeg for periodical checkups, eg. for monthly bloodwork, therefore necessitating an urban Transplant Clinic visit every six months. This visit did not coincide with the researchers' study time frame. This was corrected for by contacting the patients by telephone. Once consent was received, the researcher conducted one interview by telephone and met with and subsequently interviewed the second individual while they were visiting Winnipeg on a business matter.
- b) Individuals did not meet the relocation criteria. From the sub-sample of thirteen individuals initially approached by the researcher, six individuals did not fit the relocation criteria. Two of these individuals lived in Winnipeg previous to commencing their dialysis treatments and four lived in medical boarding homes/hostels (temporary relocation) while undergoing their dialysis treatments (Figure 1). These individuals' comments were recorded and are contained within this research.

Case studies were obtained from the consenting individuals (Appendix 1). This non-statistical method was selected because of the small numbers of individuals

available and it also served, within the ethnographic context, as the basis for the working hypothesis/conclusions of this research.

Through clinical observation, interviewing, referral from staff and/or previous researchers, and through the patients who consented to be interviewed, the researcher attempted to locate the individuals and the settings anticipated to provide the most useful information about the research question - the impact of relocation on the patient and family.

This information was arrived at through the Grounded Theory approach. This is not a linear approach but rather, "it allows for the emergence of concepts out of the data - in a schema that allows for interpretation, intuition, ruminating as well as analysis in the traditional mode" (Orona 1990:1248).

In order to obtain the case studies, research criteria have been established. These criteria and the methods of eliciting data within the criteria were addressed using the following questions:

- a) What are the parameters of the term relocated?
- b) What is the demographic/clinical profile of the patient within the overall study group prior to transplantation, eg. ESRD therapy, dialysis, etc.?
- c) What are the parameters of the term impact?

The criteria for Relocated consisted of those transplant recipients who had lived outside of a dialysis health centre area during their renal replacement therapy and had to move alone and/or with x numbers of family members to a treatment centre.

The patients and/or staff were queried to discern the individuals who had to relocate for their renal replacement therapy. The responses were validated by asking the patients if they had to move permanently, either alone and/or with their family, in order to undergo kidney dialysis treatments. The present city address contained on their medical chart was unreliable as an indicator, since, in some cases, patients who had previously relocated had elected to make the city their permanent home following their transplant surgery. A reserve or Native community address did not necessarily indicate that the patient returned to their home community because they successfully completed a kidney transplant. Economic factors or family responsibilities have been the reason for their choice of residence.

The demographic/clinical profiles of the patients in the overall study group are diverse. Several factors contributed to this diversity, including: the primary diagnosis varied; the temporal factor of when dialysis was begun and completed deviated; there were different treatment modalities and also varied concomitant effects; and the involvement of family and support groups differed. These diversities were recorded with the individual case history.

Impact is defined as an

...alteration - an improvement or deterioration in the general well-being of the population experiencing the effects of development. Impacts are viewed as external agents inducing change in such entities as behavior, attitudes, values, quality of life, friendship networks and so on (Waiten 1989:5).

Potentially, impacts may be manifested in any number of ways, negatively e.g. unemployment, financial problems, marital and/or family difficulties or in positive ways such as, new productive economic opportunities or increased family and agency support.

Interviews were recorded through note taking after having received the individuals' consent (Appendix 1). The family members and the health care workers' responses were coded differently from those of the transplanted patients, as these individuals had different exposures to the process of relocation as opposed to the patient. Interviewing sessions were restricted to approximately 60 minutes, so as not to impose an excessive demand upon the strength or time of patients and their families. As a consequence of this strategy, multiple sessions were occasionally required. In these cases overlapping validation was utilized to evaluate continuity. This was accomplished by rephrasing questions from a previous interview and determining if the responses corresponded in kind with previous replies.

Text and brief patient summaries from previous interviews of patients on long term dialysis conducted by Kaufert et al were used to elicit questions concerning relocation.

The subjects of this research were the individuals who have experienced relocation necessitated by their dialysis treatment. If a family member accompanied the subject to the Clinic, they were incorporated within the interviewing framework.

The family member data obtained in this manner was coded separately from that which was received from the subject.

Subjects were asked to give an overall account of their experiences specific to their ESRD relocation. This broad account provided the bases for themes from which further, more specific questions were constructed. Therefore, by employing the Grounded Theory Approach, a basis was determined from which to elicit the pertinent research questions.

Data, for the purposes of this research, was collected retrospectively, that is, ... "based on past data or past events" (MacMahon & Pugh 1970:44). By employing this method, it may be equated with the life history method of data collection where "... the whole life course is seen from the point of view of the person as he is currently trying to make sense of his relationship to past events, and he may not remember or choose to emphasize the things that were once important" (Watson 1985:3). Although retrospective studies utilizing the life history approach are viewed as an acceptable method of studying the medical careers of individuals, the strategy contains the potential for incorporation of several biases. Therefore, in order to be aware of and control for these biases, the process of triangulation was employed.

Triangulation, defined, suggests that there must be "...comparison of data relating to the phenomenon but deriving from different phases of the fieldwork, different points in the activity within a setting, or the accounts of other participants in the setting" (Long 1984:97).

Several factors can prejudice or influence the data collection. The retrospective method contains the potential for admission of several biases of which examples of these will be discussed and possible solutions will be examined.

Recall bias in case-control studies may result when "questions about specific exposures" [to illness] "may be asked several times of cases but only once of controls." (Sackett 1979:62). Recall bias pertaining to cases may be an important factor in this research, considering that the ill individual is more likely to remember and stress the events leading to the illness as opposed to those individuals (the family and health care personnel) who are physiologically unaffected by the renal disease. The relocation event may have occurred several years previous to the interview and the patients responses to the interviewers' questions may be tempered positively or negatively with time. Some of the experiences may have been forgotten or only the most traumatic instances recalled. Therefore, the accuracy and the amount of information attained must be questioned. The renal patient will recall his/her illness career in different ways from "significant other" individuals, eg. family, health care personnel, physicians, and social agencies. These latter individuals have entered into the patients medical careers at different times, providing different levels of medical and/or personal help and have imparted varying degrees of influence upon the patient. Therefore, these individuals cannot be expected to have the same memories of a particular portion of the patients life history - their trajectories will differ. Trajectory is a term defined ..."to refer not only to the physiological unfolding of a patient's disease but to the "organization of work" done over that course, plus the "impact" on those involved with that work and its

organization" (Strauss et al 1985:8). An awareness of this concept was necessary in order to be conscious of the different frameworks the patient/family and health care personnel were working in and between.

Triangulating the data in order to provide checks on what was observed and what has been recounted has been utilized to overcome this bias. The patients accounts were compared with "significant others" accounts, using the same subject and the same time frame.

The "one-sided reference bias" is one where "the authors may restrict their references to only those works that support their position" (Sackett 1979:61). By restricting specific questions only to the negative effects of relocation, it might be assumed that these are the only impacts to the act of relocation. The researcher must be aware of her own biases before entering the field. The literature review generally suggested only negative effects result from the act of relocation. By eliciting positive comments along with the negative, a more balanced viewpoint was encouraged.

Confounding bias occurs ..."when two factors or processes are interrelated, or "travel together", and it is incorrectly concluded that one of the factors is the causal agent" (Fletcher 1982:8). Relocation may be viewed either positively and/or negatively, depending on the reasons for migrating from the home community. Initially, relocation may have resulted from economic motivation, e.g. finding employment in a larger centre and once living in this larger centre, the migrant developed ESRD. Therefore, if the processes of when and why the initial relocation occurred are not clarified in the

collection of the data, confounding bias will result. Therefore, the patients were asked on the initial interview if they had to move alone and/or with their family member(s) specifically for treatment of their ESRD. This method of questioning was attempted in order to determine when and why the relocation took place.

Selection bias occurs when "observations are made on a group of patients that have been assembled incorrectly" (Fletcher 1982:6). Informants for research may be "selected" because they are gregarious and enjoy discussing their past medical history or they may be "rejected" because of language communication differences. Concerted attempts, using triangulation were employed to obtain information from non - English speaking individuals and this was accomplished by using, a MSB interpreter. The interpreter conveyed the purpose of the research to a Cree speaking individual from this study group and it was determined, through translation, that the individual did not have to permanently relocate to Winnipeg, but rather lived in a MSB medical boarding home and experienced "no problems" with that form of accomodation. A bias may have resulted with the use of the MSB interpreter. The interpreter may or may not have placed emphasis on particular issues or by her presence during the interview may have influenced how a question was answered.

The researcher was aware that the patient, the family, and/or the health care personnel, may have presented a dramatized and possibly exaggerated version of their perception of the event and that these accounts were related to a clearly sympathetic listener (West 1990).

Realistically, the resources were not available to control all the relevant variables. An awareness of the confounding effects were recorded with the collected data.

The accounts which were collected depended upon, the type of accounts that were elicited and the time frame, the setting and the extent to which these accounts were derived. The concept of "time", as viewed by Native patients, differed from the hospital or institutional concept of "time" along with the researchers own cultural perceptions. The subjects were interviewed at different stages of their illness careers and the process of how they made sense of their present illness combined with their past illness would also possibly differ.

In collecting these accounts, the researcher was aware that there are different types and levels of discourse. There are public accounts, public talk and private accounts and private talk. These are defined as follows:

Public accounts refer to "sets of meanings" which affirm or reproduce the moral order or dominant ideology, and are in essence "ought" type expressions of an approved or acceptable kind.

Public talk is talk in terms of the "generalized other" whether or not it is actually believed and may have the quality of a "managed appearance."

Private accounts refer to meanings derived from the experiential world, a reality which may be altogether different and potentially much less acceptable.

Private talk may reveal a deviant or "darker" side of things and typically occurs between confidants who share, or are granted access to that reality" (West 1990:1229).

Therefore, the conditions from which the accounts were produced were identified and recorded. "This is one way in which the status of what they say and its validity for a sociological account may be judged" (West 1990:1230).

DATA MANAGEMENT: Data management was initiated with the biographical narrative employing a loose format utilizing a conversational approach. This consisted of asking general questions of how the relocation began and then directing the narrative flow in a chronological order to the present time frame. Notetaking was curtailed to brief notations of key words while conducting the interviews. These were added to and/or expanded upon immediately following the interviews or when the patient was called into a room to be examined. The interview continued once the patient returned to the waiting area from their Clinic appointment. The researcher enlarged the notetaking to include the context in which the interview took place and the individuals' verbatim and/or paraphased responses were recorded in detail. The method of tape recording the interviews was not feasible given the limited space and lack of privacy for the participating individuals. The entire transcribed notes were evaluated in order to obtain a broad, overall sense of the patients accounts of the events pertaining to relocation. Care was taken to ensure that the researcher did not impose her own categories on the different segments of talk. Therefore the ethnography was composed"not as a report on people but a report on the encounter ..." (Kirk 1986: 68). The researcher was also cognizant of the fact that she was not only to consider the individuals' responses but also what was not discussed in the interview. The individuals may have found their current living conditions deplorable in relation to their previous

accomodations but may have been either embarrassed and/or did not wish to share their opinions with the researcher.

The narratives were paraphrased utilizing the patient/families words and concepts. This involved writing notes and impressions on the margins of the transcribed text. This paraphrased text was validated by the subjects through eliciting their responses as to the texts' accuracy or by rephrasing questions from previous interview sessions.

The second step in data management involved manually coding the text. This method ensured careful and accurate key wording.

The third step included compiling thematic profiles which in chronological order contained the information on the subjects careers. A chart, Figure 2 was developed, indicating the various levels and degrees of interventions identified from the data (Gerhardt 1990).

The researcher was sensitive to when she had reached a saturation point in the amount of information she was to obtain. This may have resulted from the fact that the interviews were not conducted in optimal conditions and/or the individual had nothing else to offer on the subject of relocation.

QUALITY CONTROL: Qualitative research, which historical biographies utilize, are ... "socially concerned, cosmopolitan, and above all objective" (Kirk 1986:10). Objectivity is evaluated in terms of reliability and validity. "Reliability is the degree to which the finding is independent of accidental circumstances of the research and validity is

the degree to which the finding is interpreted in a correct way" (Kirk 1986:21). The researcher took on the role of the cynical introspectionist, in order to give the data the most rigorous data-quality evaluation as possible (Smith 1981). Reliability and validity are not symmetrical and perfect validity is difficult if not impossible to obtain. Validity is often judged on the face of things and other factors are not taken into account. These factors included questioning whether what the researcher actually observed was actually what she thought she had observed.

There are three types of validity which must be controlled for, including:

Apparent validity: "The obviousness of the relationship between an observational procedure and what it is attended to observe."

Instrumental validity: "The correspondence between an observation and a different and accepted observation of the same thing."

Theoretical validity: "The quality of the relationship between an observation and the element of a model that represents it" (Kirk 1986:79,80).

One must be satisfied with the internal validity of the research but also must be concerned with its external validity. One method of meeting this satisfaction was to provide a reflexive account of the research, including the researchers own role in conducting the research. This was accomplished by maintaining a separate, private, journal containing personal thoughts on the experiences obtained during the research process. The researcher was aware that in providing this "personal thought" type of account, she may not have been completely truthful in print. By stating these recorded thoughts in her final thesis, and if read by the subjects and/or agency and service representatives, misconceptions as to its relevance might occur.

The researcher has attempted to identify and control for biases and to ensure reliability and validation but there is "no absolute truth against which an account may be prepared.." only other accounts (West 1990:1230). "All the most objective researcher can report is his version of the actions and decisions of others and how they see their world" (Long 1984:97).

CHAPTER III: MEDICAL CONTEXT OF HEALTH CARE DELIVERY IN ESRD

"Managing chronic illness doesn't occur in a vacuum but rather it is firmly wedded to the social context in which the illness is experienced" (Pinter 1988:85). Comprehension of the overall complexity faced by a Native individual within the chronicity of ESRD, may derive from a consideration of the various social and medical contexts in which that patient and their families must operate within and between. In this context the patient is viewed as the focal point of a network within which the relevant social and medical contexts intervene and interact.

The following brief synopses of these medical and administrative contexts are provided to facilitate understanding of the succeeding chapters within this presentation. Not all of these contexts are Native specific.

MEDICAL CONTEXT OF HEALTH CARE DELIVERY ESRD TREATMENT:

The symptoms of early kidney disease may be managed by means of special diets and medications as well as regular attendance at one of several clinics which operate from HSC and or SBGH. For some patients, complete kidney failure is perceived to originate spontaneously while other patients are aware that their kidney functioning will eventually fail. The guidelines for the commencement of dialysis and/or for transplantation vary as to the individual patient. These consist of, a) a decreased kidney functioning rate compared to their normal rate and b) elevated levels of creatinine (a waste product of muscle activity) and urea (a waste product from the break down of protein). Dialysis or transplantation occurs when the individual's disease is considered

to be such that initiating dialysis or performing a transplant will assist in alleviating the symptoms of the disease. Some patients bypass the dialysis procedure and receive a transplant without experiencing dialysis. This therapeutic circumvention occurs if a compatible kidney donor is immediately available.

There are two types of dialysis treatments, hemodialysis and peritoneal dialysis. Hemodialysis is accomplished with the use of a dialysis machine. Blood is mechanically drawn from the patient's body, passed through a dialyzer and returned to the patient. The function of the dialyzer is to separate the patients' soluble wastes from their blood. The bloodstream is accessed by using one of the following methods, fistulas, grafts, or catheters. The time required to undergo hemodialysis is between 9 and 15 hours a week, generally 3 to 5 hours per treatment.

Peritoneal dialysis does not use a machine to remove the waste products from the body's fluids but rather uses the peritoneum, the membranous lining of the abdominal peritoneal cavity. The peritoneal cavity is filled with a special dialysis fluid and this exposes the blood vessels in the peritoneum to the fluid. The peritoneum acts in a manner analogous to the cellophane membrane in the dialyzer and the excess water and waste products within the venous circulation of the peritoneum pass through the membrane and into the dialysis fluid. The fluid and wastes are subsequently drained from the body and discarded. The process is then repeated. Catheters are used to establish access to the peritoneal sites. There are two procedural variations of peritoneal dialysis: Intermittent peritoneal dialysis (IPD) and Continuous peritoneal

dialysis (CAP). CAP, in turn consists of two types of dialysis: Continuous Ambulatory Peritoneal Dialysis, (CAPD) and Continuous Cycling Peritoneal Dialysis (CCPD)

In IPD, the dialysis fluid is left in the peritoneal cavity for a short time period and then drained. CAPD is a method in which the patient holds about 2 litres of dialysis fluid in their peritoneal cavity at all times. About four times a day, the patient drains out the old fluid and replaces it with two more litres of dialysis fluid. These exchanges are done at regular intervals throughout the day and last 30 - 45 minutes each.

CCPD is a method whereby a machine, called an automatic cycler performs the exchanges during the night while the patient sleeps. In the morning, about 2 litres of dialysis fluid is left in the peritoneal cavity for the day and this is eventually drained out in the evening when the patient is connected back up to the machine.

MANITOBA LOCAL CENTRES DIALYSIS PROGRAM (MLCDP) - RURAL RENAL DIALYSIS PATIENTS: There are 7 local dialysis treatment areas in Manitoba and northwestern Ontario.

The objective of the Local Centre Program is to eliminate the need of relocating the dialysis patient, thereby attempting to avoid the accompanying disruption to their lifestyle.

The patients which use these local facilities are those whose disease is of a chronic, non-emergency nature. The location of these centres and their subsequent complement of dialysis machines depends upon the number of individuals requiring

dialysis within the area; the size of the community and the distance from a current centre.

Patients enter this program through referral to the Medical Director. The referred patients include those who have been or are currently being dialyzed at the Regional Centres at HSC and SBGH in Winnipeg and those that are not in the HSC system and have been dialysed at SBGH or outside the province. A multidisciplinary team assesses the patient while they are in chronic renal failure and are advancing towards ESRD. The patients' name is placed on a Provincial List.

Prior to transfer to the Local Centre, the patient must be dialyzed at the HSC (hemodialysis) or S.B.G.H. (IPD). This is to ensure that the patient is medically stabilized, that the patient is compliant and that an assessment of the various support services has been determined. The patient is instructed, and should understand, that it is a privilege to be placed on the Local Centre Dialysis Program. The patients must also understand that they do not have access to the clinical expertise that they would have if they dialysed in a large urban centre. Follow-up clinics for these rural patients are held the first and third Thursday of the month.

Affiliated with the MLCDP is the Home Care Program. The objective for the development of this program was to maintain the dialysis patient in their home community, thereby eliminating the necessity for relocating the patient to a larger treatment centre. Patients are initially taught their dialysis procedure by a nurse, with each patient having their own equipment. Before dialysis patients are released to do

their treatment within their own homes, a partner must also be trained. The partner acts as a back-up in case the patient is too ill to perform their own dialysis. Certain physical criteria pertaining to the home are addressed. For example, there must be an adequate and clean water supply and drainage, enough room for both the equipment and the storage of the supplies, and adequate heating. These criteria are viewed as significant problem areas and impediments to home care, especially for northern patients.

TRANSPLANTATION: A kidney transplant is not an indicated procedure for every patient with ESRD. The patient's age and their history of extra-organ disease in other organs are criteria in determination of the suitability of the individual for renal transplant.

There are two types of kidney transplants, those which are received from a living donor and those which are received from an individual who has died suddenly (cadaveric). The living donor transplant is usually obtained from a genetic relative while the cadaveric transplant is generally received from a young, previously healthy donor.

The Transplant Program is operated by the province of Manitoba and is not affiliated with any of the urban hospitals. The transplant surgery and the subsequent follow-up Transplant Clinics are carried out at the Health Sciences Centre.

IMMUNOSUPPRESSIVES: The most frequently prescribed immunosuppressive medications are cyclosporin and prednisone. Cyclosporin is a drug which is given

before a transplant is performed and daily for the life of the transplant. Although the mechanism of this medication is not completely understood, it appears to prevent rejection cells, called lymphocytes, from acting effectively in graft rejection. The main advantage of this drug is that it does not suppress the development of other blood cells. Blood tests are utilized to determine the cyclosporin levels but the results are individualized. Some patients experience no rejection with low doses of the drug. Other medications, such as antibiotics and anticonvulsive drugs interact with the cyclosporin. Therefore constant monitoring of the medication level is imperative. The side effects of cyclosporin include the growth of fine hair on the upper body, slight gum enlargement, mild tremors, high blood pressure, toxic effects to the kidney and liver when medication is given in high doses, and rare occurrences of certain types of cancers (lymphoma) (K.F.C. 1991: 4- 7).

Prednisone is a steroid which reduces inflammation and helps to suppress rejection. The side effects of prednisone are as follows: weight gain (predominantly on the face and neck), increased facial hair, and mood swings. Some of the possible long-term effects are cataracts, weak leg muscles, joint problems, and diabetes (K.F.C. 1991:4-8). Insulin interacts with prednisone and since many ESRD patients are also diabetic, careful monitoring of their insulin and prednisone levels is imperative.

Other immunosuppressive medications which may be prescribed to post-transplant patients include Solu Medrol and OKT 3 (Orthoclone).

TRANSPLANT CLINIC: The goal of the Transplant Clinic medical staff to the "follow-up" of the post-transplant patient is to "allow the patient to lead an active, productive life and to detect complications as early as possible" (Transplant Clinics' Nursing Manual).

Following the surgery, a Transplant Clinic nurse visits the patient on the Transplant Surgical Unit and explains the Clinic's procedures. These procedures are as follows: the Clinic operates daily from 0800 hours to 1130 hours, except on weekends. Newly transplanted patients are seen daily in the Clinic for the first month after discharge, and on the weekend visits the Transplant surgical unit, in order to be examined. As the patients' condition becomes stable, the follow-up visits are reduced to approximately four to six week intervals.

The Transplant Clinic consists of a waiting area shared by four other clinics, although all do not operate at the same time. The waiting area consists of an arrangement of benches along one side of a hospital corridor with an opened Nursing Station off the corridor, opposite the seats. A closed room next to this station, contains individual working stations for each of the nursing staff along with the patient's charts.

Ideally, each patient has an appointed Transplant nurse, but because of various working arrangements and the patients schedules, this method is not always possible. Some patients arrive with family members who wait until the appointment is completed, other patients arrive alone. The patients are greeted by either the Unit Clerk

or a member of the Nursing staff and the patients receive a requisition for their blood work, which they take to the Hematology Department.

Some patients arrive on the unit carrying a dark blue plastic bag which contains their 24 hour urine sample. The patient picks up a requisition from the Unit Clerk and places the specimen on a cart mid-way down the hallway. The patient may also be required to take specimen containers which are stored on the cart and provide specimens for urinalysis, eg. mid-stream urine (MSU). This is accomplished by utilizing a washroom adjacent to the cart. The containers are labelled by the patient and are also left on the cart. The number of times these samples are collected varies and are individualized depending on the patients' condition.

Diabetic patients have a fasting blood sugar procedure obtained on each Clinic visit. Annually, all patients have a physical examination, including a chest X-ray, and EKG. At 1, 3, 6, and 12 month intervals patients have a Doppler Ultrasound which measures the blood flow in the kidney. Patients are weighed on every visit and newly transplanted patients are orientated to the Transplant Unit. Their medications are explained to them and appointments are made for them. Their temperature is taken daily during the first month post-transplant for signs of inflammation or infection.

After patients have completed his/her blood tests and has returned to the Clinic area, they are called by the nurse and taken into one of several examination rooms. One of the examining areas is surrounded by a curtain screen, the other two rooms are enclosed by a door. The room is furnished with an examination table, a desk and two

chairs. The patient sits or lays on the examining table. The following procedures are performed by the nurse: The pulse is taken and recorded; the blood pressure is taken, laying down and standing and recorded; and the medication is reviewed.

The following medications are commonly taken by renal transplant patients. Prednisone, Azathioprine, Cyclosporine A, Chlorthalidone, Furosemide, Ferrous Sulphate, and Solu Medrol. The nursing staff are aware of the indications, contraindications, precautions, adverse effects and usual dosages of all the drugs used for renal transplant patients. Patients have the opportunity of obtaining their medications from the hospital pharmacy or by attending a public pharmacy of their choice.

Once the patient leaves the examining room, they wait either at the nursing station desk or return to a seat in the waiting area until they receive instructions regarding future appointments. The patient must be available, thereafter, to receive information by telephone regarding the results of their blood tests from the previous Clinic visit. These results may indicate a change in their medication dosage and this is subsequently relayed to the patient.

The Clinic atmosphere, as observed from my initial introduction to the Clinic staff in April 1990 to the present time, is one of a relaxed, friendly nature. The nursing and support staff (unit and ward clerks) provide a casual atmosphere for the patients. Joking relationships are evident both between staff members and between staff members and the patients. The post-transplant patients have commented favorably upon the Clinic staff. One patient stated that although the Clinic staff were pleasant and fun,

"they are good at knowing when you are stressed". This joking behavior was also directed towards my frequent appearances at the Clinic. Conversely, the staff were empathic to my role as a researcher and to the time spent waiting for patients to arrive for their appointments.

The transplant physician staff stand in the corridor at the open nursing station to write orders or comments on the patients charts. Since the waiting area faces the opened nursing station, transplant patients' appointments for related tests, eg. bone scans and biopsies are made within hearing distance of all the Clinic patients and family members sitting in the waiting area.

ADMINISTRATIVE CONTEXT OF HEALTH CARE DELIVERY:

a) **MEDICAL SERVICES BRANCH:** The Medical Services Branch (MSB) is one of four main programs administered by the National Department of Health and Welfare. Provision of primary health care to status Natives and all residents of the territories is included within the MSB mandate. Briefly, this service has as its primary goal that of ..."improving the level of health in Indian communities" (Introduction to Medical Services 1988:3). The organization of the MSB (Manitoba Branch) is depicted in (Figure 3).

Public Health nurses supply health services to Indian reserves in Manitoba including home visiting, education and counselling. Medical, dental and eye care are available by visiting specialists. Native language translation is usually available and transportation is provided for those in need ... (Native Organizations in Manitoba).

The services which are provided by MSB to individuals who must travel to a medical centre include accommodation, food and transportation. They also cover the cost of an escort where one is necessary, eg. the patient does not speak or understand the English language or the patient is too ill to travel alone. The accommodation is provided in a medical boarding home. If the patient wishes to stay in private accommodations, they are reimbursed approximately \$40.00 a day. While staying in the boarding home, the patient is provided with food and a living allowance.

MSB also provides services to the Status Native once they leave the Reserve and come into the city. This service is sustained until the patient completes their active treatment. If the patient decides to remain in the city, thereafter and they do not have any other form of financial assistance, they must make other arrangements, eg. with Provincial Social Assistance.

Once the patient/family decide to relocate and if the patient is classified as the "head of the household", they are placed directly on Provincial Welfare. If the patient is not designated as "head of the household", they receive city welfare for a three month period and then they are "turned over" to the Provincial Welfare Department. Any services which the Provincial/Municipal Welfare provides are billed to MSB at the end of the year.

MSB receive their referrals from nurses and doctors in the communities and from Native agencies in both rural and urban centres.

If patients must stay in Winnipeg for extended periods of time, e.g. the ESRD patient, MSB arranges and pays either for return visits to their home community or for a family member to visit the city.

The decision to relocate must be made by the patient/family. Once the individual comes to the city, MSB meets with the patient and family and a "Letter of Agreement" is negotiated. This letter provides a mechanism for that individual to receive accommodations and their special diet. MSB will pay for the individual if they are in the city and become sick while in the city. This provision is made out if the province refuses to provide some financial services to the patient. Monies are sometimes attained from a variety of different sources and individuals can be referred to various agencies which offer different programs than those delivered by MSB.

b) MEDICAL BOARDING HOMES: There are five MSB medical boarding or receiving homes in Winnipeg. The researcher was invited on a tour of one of these facilities and observed a large, clean building which appeared to be efficiently run and provided comfortable accommodations. Rooms were homey and uncrowded, bathroom accommodations were provided en suite for most rooms. Areas were provided for watching television, reading and conversation.

At the time of observation, the boarding home was licensed for 25 people and was in the process of increasing its' complement to 29 beds. There is no elevator in the building - a ramp leads from the front porch into the first floor area. The facility has an institutional kitchen where care is given to special diets, such as for dialysis patients,

and snacks are provided for diabetic patients. Meals are on a regular schedule and meal planning is guided by the HSC and S.B.G.H. renal disease dieticians.

All the staff are trained in First Aide and their skills are updated regularly. The boarding homes are regulated under MSB and the Province, eg. they must meet fire regulations, etc. and are inspected regularly.

Medical boarding home patients are Status Natives who live on the Reserves. If patients are Status but, for example, live in Pine Falls (off the Reserve) their accommodation and expenses are not covered by MSB. The individuals who are unable to privately pay for these services may apply for Provincial Social Assistance. Patients can request a certain home and if there is space available, they will be accommodated - if there is no room available, they will be placed in one of the other four homes. If all the boarding homes have their complement of patients, the Balmoral and/or Maryland Hotels are used by MSB to provide accommodation. Some patients, if they are aware of future appointments, will book their accommodations ahead from one visit to the next. Some Native individuals request specific homes for several reasons. These include: they enjoy the atmosphere in a particular home; their Native language is spoken in that home; friends are staying in that particular home; or its' been recommended as a good place to stay. If individuals are willing to pay for their own accommodations, they stay in hotels of their choosing.

MANITOBA SOCIAL ALLOWANCES PROGRAM - INCOME SECURITY: The Manitoba Social Allowances Program is provided by the provincial government and receives its' mandate from the Manitoba Social Allowances Act.

Services which are considered essential include ensuring that no Manitoban resident lacks (a) such things, goods, and services as are essential to his health and well-being, including food, clothing, shelter, and essential surgical, medical, optical, dental, and other remedial treatment, care, and attention; and (b) an adequate funeral upon his death (Social Insurance Act:BO 01 03:1989). The amount to be paid is decided after consideration is given to the recipients basic necessities and those of his dependants. These rates, eg. rental rates, are intended to be used as guidelines. The individual patient and/or family attempts to locate accommodations within the guidelines.

Recipients or "clients" are maintained on City of Winnipeg Welfare for a period of 90 days. After this 3 month period, the individual is placed on the Social Allowances Program. Placement is effected for those individuals"who, by reason of age or by reason of physical or mental health, or physical or mental capacity or disorder that is likely to continue for more then 90 days" (Social Allowances Act BO,01,04).

In order to become a recipient of the programs' disability benefits, the individual must apply and provide medical evidence of their disability and, in turn, this is reviewed by a medical panel. The recipients eligibility for Social Allowance based on disability can be established by this panel for a period of up to two years before it must be re-assessed. The disabled persons' eligibility for Provincial Social Assistance is deter-

mined by the following criteria. If the disabled person is designated the head of the household, that individual and all their dependants' under 18 years of age receive the benefits from Provincial Social Assistance. Since they have been classified as disabled, they are not required to apply to City Welfare (which is a temporary form of assistance) nor are they required to wait the 90 days on City Welfare before applying to the Provincial Welfare. If there are any dependants over 18 years of age who require social assistance, they must apply separately to the Provincial Welfare Department. The term "head of the household" also applies to single mothers. Recipients must also meet the programs financial eligibility by conforming to the allowable liquid asset guidelines.

The recipients receive a Health Card which is presented when requesting prescribed medications, dental and optical prescriptions. Medical Transportation is also provided via taxi vouchers. The patients' special diet must be prescribed by the attending physician and the financial allotment is adjusted to pay for these added costs.

Out of province patients receive the same allowances as residents of Manitoba, as long as they have met the three month residency requirement.

**SOUTH EAST RESOURCE DEVELOPMENT COUNCIL - MEDICAL INTER-
PRETERS PROGRAM:** The Southeast Resource Development Council (SERDC) was incorporated, and recognized by the Canadian government, in 1978. This Council unites eight member Reserves, with status as First Nations, and serves approximately 5,000 members. The SERDC operates under the mandate of assisting in the transfer of local control of, and responsibility for services and programs to member First

Nations. The Medical Interpreters Program is administered under the Advisory Services part of SERDC.

The Medical Interpreters' Program has as its main goal the provision of "... effective communication between patients of native ancestry with hospital medical staff." This is undertaken through the translating of doctor's orders and ..." explaining to the doctor as precisely as possible, what the patient's problem is" (SERDC Brochure). The program also provides support for temporary living arrangements and also escorts patients to and from hospitals, hotels/motels, airports and/or bus depots. These services are provided upon the request of MSB. This program extends its services to all clients of Manitoba as well as to individuals from Saskatchewan and Ontario.

The Medical Interpreters Program (MIP) provides services to: Medical Services Branch (MSB), the Bands and to all Winnipeg hospitals that have need of interpreting for Native patients. The MIP works together with the interpreters in the respective hospital based Native Services Departments. The MIP also works within the community, coordinating the various agencies, institutions, and individuals in the process of relocating dialysis patients. The MIP generally receives patient referrals from the hospital social worker, who in turn receives "a letter" from the patients' doctor. The doctor documents the reasons why it is necessary for the patient to relocate. The MIP then proceeds to determine the size of the family and the extent of their financial need. (If the assistance is from the patients' home Band, the MIP determines the amount and the timing of the last Band payment).

The MIP workers inform their clients of the differences in living in an urban center. They offer advice regarding the life skills that they will need in the city, eg. the various welfare processes and shopping information.

The decision to relocate must be made by the patient and the family. If they decide to relocate, the various issues that they must face by moving to the city are explained to them by MIP. If they decide to move, the MIP co-ordinates the move.

The MIP obtains available housing vacancies by checking the newspaper classified ads and by contacting landlords. The house/apartment must be accessible for the dialysis patients eg. not a basement apartment nor one where the patient must climb stairs. This housing should be in close proximity to stores for food shopping; to schools; to laundry facilities and to hospitals. It is very difficult to find a combination of all of the above factors when trying to locate accommodation for dialysis patients. When school age children are involved in the move, the MIP must also make certain that the children are enrolled in a school.

Loneliness is seen as a problem, especially if the patients do not have their families with them. Problems with shopping for food which is required for the patients' special diet were also identified as issues for the relocated Native dialysis patient. MIP ensure that patients and families are placed in contact with other people from their home area.

DIALYSIS SUPPORT GROUP: This group was developed in response to the observations of several individuals working with patients who had to relocate for the purpose of medical treatment. Individuals undergoing treatment for kidney failure comprised the largest numbers in this group, whose principal difficulty was in obtaining clean, warm housing. The Support Group meetings are generally held on a monthly bases at the St. Helen's Anglican "Ayamihewkamik" (House of Prayer) Church, 242 Manitoba Ave., Winnipeg.

Committee members ensure that the dialysis patients are notified of meetings and transportation is arranged and provided by MSB, using Thunderbird Transportation. Interpretive services are also provided and various programs are prepared. Guest speakers present information regarding some aspect of living with kidney disease. The topics for these presentations are recommended by the patients. The numbers of individuals who attend the meetings varies from 4 to 9 individuals but on certain occasions e.g. Christmas Party and the Closing Picnics, between twenty-five and one hundred patients and family members attend. The presentations which were observed included programs pertaining to the: Kidney Transplant Program; two programs pertaining to diet; a Christmas Party; Medications; Open Meeting; Kidney Foundation and a Closing Picnic.

DIALA LIFE - HOUSING PROJECT: This group evolved from the Dialysis Support Group which had indicated that there was an urgent need for clean, warm, affordable housing for medically relocated Native individuals. A committee was formed consist-

ing of various community and professional individuals. A Consultant service was chosen to coordinate and advise during the planning and research of this project. From the larger committee group, a Board, consisting of Native individuals was established. This Board was, and continues to be, responsible for the presentation of informational briefs to the various governmental agencies and for obtaining approval for the project funding from the Provincial Ministers responsible for Health, Housing and Native Concerns. At present, an appropriate location has been obtained for the construction of a thirty-six independent-living unit. This housing will provide accommodations for relocated Native patients and their families who have chronic medical conditions.

CHAPTER IV: HYPOTHETICAL CASE STUDY

A patient identified as manifesting symptoms of ESRD, may be confronted with a complex set of medical and social interventions. These are intended to facilitate restored function on a day to day basis and, thereby, to effect continuation of the patient's life. If the patient does not reside in close proximity to a treatment centre, further interferences occur. If the patient is a Status Native, the significance of these interventions is magnified.

A Native dialysis patient who has decided to relocate to be near a treatment facility also decides, knowingly or unknowingly, to live by another set of rules than the non-Native dialysis patient. The Native patient who becomes ill must not only cope with their illness but also with all the institutions and the bureaucracies which have evolved to perform specific functions for the Native patient.

The following quote succinctly demonstrates the multitude of problems the Native individual encounters when they are admitted to the health care system.

Native patients admitted to large urban hospitals from remote northern communities or reserves, and Metis communities in other areas of Saskatchewan, encounter a multitude of problems in addition to the illness, that prompted their referral. The long and expensive trip to the unfamiliar world of the large city, finding decent, affordable accommodation before and after admission, getting around in the urban maze, and buying meals are some of the challenges -- complicated by language and cultural barriers. In the hospital, health clinic, or doctors office, unfamiliar medical technology, procedures and terminology, racial stereotyping and prejudice, again compounded by language and cultural differences, misunderstanding, loneliness, and confusion that result, detract from the intended healing process. They negatively affect the patient's response to hospital care, and limit compliance with post-discharge follow-up treatment.

The result, is increased hospital utilization and decreased effectiveness of medical care (Saskatoon District Tribal Council - A Proposal 1989:1).

In order to understand the numerous interventions which a Native ESRD patient encounters, we will follow the medical career of Patient T. Patient T.s' experiences are reported in the form of a hypothetical case study, developed as a composite ethnography of a transplant patient whose experiences mirror a subjective "average" of all the patients interviewed for this study. The male gender is attributed to this hypothetical patient, since males constituted the largest group interviewed in this research.

PATIENT'S MEDICAL CAREER - "THE ILLNESS ITSELF":

Four years ago, Patient T. and his family lived on a reserve several hundred air miles north of a large urban city. T. worked for a construction company, an hours drive from his home, and he fished in his free time. T.s' wife worked part time in one of the local stores and his three teenage children attended school in their community. T. and his family considered themselves fortunate to have jobs as their reserve suffered from high unemployment rates.

T. prided himself in the fact that he did not take "sick-time" from his job. He always told his family and his friends that he had never "been sick a day in his life." But suddenly he became aware of physical symptoms, ones which neither he nor his family were able to ignore. T. noticed that he became extremely tired and short of breath for no apparent reason. He noted swelling in his feet and hands. Several years before the onset of the present symptoms, he had been told by a doctor that he had high blood

pressure. The doctor that he visited prescribed some medication for his elevated blood pressure. T. took these pills for a short time, but believed that "they were not doing him any good," so stopped taking them. On urgings from his family, T. visited the Nursing Station on the reserve. He was examined by the nurse and it was decided to have him sent to a northern hospital, a two hour drive from his home reserve. A family member drove T. to the hospital and a physical examination and blood tests were conducted. Having received the test results, it was decided by the medical staff, to have T. examined by a nephrologist in a larger center. Once the appointment date was confirmed and since T. is a status Native and has a treaty number, the nurse from T.s' community contacted a Medical Services Branch (MSB) clerk. This clerk was responsible for T.s' reserve and works out of the MSB regional office in the urban centre. The clerk made arrangements for T. to be flown from the reserve to the city as well as for his accommodations in a medical boarding home. Since T. spoke and understood English, he did not require the company of an escort for language interpretation on this trip.

T. arrived alone at the urban airport and was met by the driver of Thunderbird, the MSB transportation van, which transported him to one of the five medical boarding homes in the city. T. has only been in the city on one other occasion, several years ago. His ride in the van to his accommodations is shared with several other Native persons. These individuals do not speak English nor T.s' Native language. He watches in silence as the vehicle maneuvers through traffic and passes unfamiliar buildings and people. The thought passes through his mind that he has seen more people on that short journey

then he would have seen in a years time in his home community. He arrives at the boarding home and is welcomed there. He has heard about this home, as being a good place to stay, from someone in his community. Since he has no family living in the city who could "put him up," this boarding home, he believed, was the best arrangement. He is shown to his room on the second floor of a large, old house. The room is warm, clean and has a complete bathroom which is entered from within the room. His roommate is another man from an area not far from T.s' home. They know many people in common and T. feels comfortable having someone to talk with. Supper is served in a dining room on the main floor. He sits at the table with several other people, some of whom have lived at this boarding home for over a year. He discovers that they return to their home communities every few months for short time periods. T. wonders how these people cope with the fact that they are ill, unable to work, and are separated from their family. After the meal, some of the people wander back to their rooms, sit on the veranda or watch television in a room adjacent to the dining room.

After breakfast the next morning, T. is again taken in the Thunderbird van and is delivered to a large urban hospital. He is left at the front door and must find a certain area of the hospital, the instructions to which are written on a piece of paper. His first reaction to this building is that it is so large and that there are so many people dressed in white and colored clothing dashing about or sitting having food along a corridor. Since T. speaks and understands English, he approaches the Information Booth and presents his paper which has the instructions as to which clinic he is to attend. He is given a map and listens to the instructions. He proceeds to follow the directions and

passes more medical people and hospital staff all appearing busy and involved in serious conversations. He finally arrives at the elevator and, thereby, to the floor where the clinic is being held. After following more signs and becoming increasingly confused, he locates the nursing station and reports to the person who is sitting behind the desk. He is told to take a seat in the hallway opposite the nursing station. T. looks around at his surroundings and sees several other patients also seated in the hallway. The staff at the nursing station are busy answering phone calls and giving instructions to various other people who appear and stand by the nursing station. After some time T. is called by name and shown into a room which contains an examination table, chairs and a desk. Two people come into the room wearing white coats whom he assumes are a doctor and a nurse. He is asked many questions and is examined by the doctor. He is told that he would have to have more tests and that these tests would be done over the next few days. He is very surprised, as he believed that he would have been able to returned to his home by the following day. He realizes that he must get word back to his family and employer that he will be in the city longer then expected. After completing the various tests over the next few days, T. returns to the clinic area which he had initially visited. He waits in the examining room and the doctor arrives with T.s' chart in hand. T is told that the results from the tests indicate that his kidneys are not working properly. He finds this fact difficult to comprehend as he is still able to urinate. He later is told that it is the quality of his urine and not the quantity of urine that is an important factor. His kidneys are unable to process his body wastes so therefore he must go on a form of treatment called dialysis. This treatment, he is told, helps to clean the wastes from his body, thereby doing the work previously done by his kidneys. T. is in a state of shock.

He has never imagined that such a thing could be wrong with him. He only partially hears phrases and words which the doctor is explaining to him. When the doctor leaves the room, T. does not know what to do. What does all this mean? A nurse arrives to explain to T. what will happen to him when he begins his dialysis, scheduled to take place the next day. T. returns to the boarding home and contacts his family by phone with the news of his illness. Their reaction mirrors T.s' initial shock. The full impact of this startling news will not be fully comprehended for many months. It will only be then that T. can realize how "scared" he was for himself and his family.

T. is told that the type of kidney disease which he has will not get better and that he must remain on dialysis for the rest of his life or until he gets a kidney transplant.

The first morning he begins his dialysis, he has tubes placed in his neck. These tubes are connected to the dialysis machine and he must lie in a bed for three and a half to four hours at a time. This becomes very uncomfortable for him. He attempts to sleep during this time but because of the noise and the constant activity of the hospital area, and the fact that he had awakened three hours previously from a nights' sleep, his attempted nap is fitful and restless. His nurse appears regularly to check on his condition, to adjust the machine and to add medications to the tubing on the machine. This time passes slowly. He checks the large clock which is positioned on the wall in front of his bed. Two more hours to go before he is released from this machine. He feels caught, at times panicking, knowing that he cannot disengage himself from this machine - his so called giver of life. Sometimes T. speaks to other dialysis patients while he waits to be "set up" on the machine and when he attends the Dialysis Support

Group meetings. But he does not feel like talking about the thoughts that are crowding his mind.

The inactivity of being on the machine provides for the heightening of T.s' awareness of many unanswered questions. T. believes his life and his future are in a state of limbo! How can he submit himself to this form of treatment indefinitely? What will his family think when they see his blood being drawn from his body and pulsed through this machine which stands, beeping and flashing beside his bed? How can he work at his old job - at times he barely has the strength or energy to accomplish the simplest of tasks? How will he and his family survive economically? All these questions would be addressed through time and through experience and accomodation.

After several weeks of using the subclavian catheter access for his dialysis, it is decided by the medical staff that Patient T. is to have surgery and a fistula is to be created. Six weeks following this surgery, the fistula is ready to be used as an access site. Shortly after this decision, T. experiences an infection in his fistula area and must return to his original method of access.

During the protracted periods of time on the dialysis machine, T. could not stop thinking about his past life. He believed that what he had accomplished in his life had been worthwhile. He had always "worked for a living," even as a young man, when he went hunting, trapping, and fishing with his father and uncles. He had considered himself the lucky one, obtaining a steady, full-time position with the construction company. Now because of his illness, the freedom and prestige of employment were no

longer evident. His wife and children saw how his illness and lack of work affected him. The husband and father they once knew only showed himself infrequently - the remaining time he spent in silent thought. T.s' physical condition oscillates from one where he feels and acts hopeful for the future for both himself and his family to one of utter hopelessness and despondency. His life has settled into a routine, one which completely revolves around his dialysis treatments and his medical condition. While he is having his dialysis he is visited by various medical staff members. These include the dietician, who explains the various foods he is allowed to eat and the reasons for his liquid restrictions; the social worker, who, among other things, helps him with arranging visits to his home; and the Native Interpreter who visits with him and provides support.

T. is informed by the medical staff that he has several options to consider in regard to the method and location of his dialysis treatments. T.s' name has also been placed on the Transplant Waiting List.

During the course of T's brief trips home to be with his family, he "goes to see" an Elder. This is an individual whom he has known and respected all his life. T. tells the Elder of his illness and that his only hope to remain alive is through dialysis and the possibility of obtaining a kidney transplant. T. expresses his fears and his feelings of helplessness in regard to his life and that of his family. There are days in his life, he explains, that he does not want to continue with his treatments - he would rather die than to face more days of uncertainty. The Elder speaks to T. in terms of hope, of a determination and a will to live. Acquiesance to his illness, the Elder cautions, is an

act of suicide. This, declared the Elder, is not the Native way. After each of these visits, T. began to feel that perhaps he could manage and live within the confines of his illness. Some days were easier than others to adopt this philosophy. T. experienced a further set back in his illness when it became evident that he had an area on his foot which would not heal. He was told that this was due to problems with his circulation. Again on one of his visits to his home community, T. visits a medicine person and consults with this individual as to the method of treatment for this problem. The medicine person prepares a mixture of medicinal herbs and T. is given the directions for their application. Through time the area heals and T. believes that this has occurred as the result of these medicines.

RELOCATION:

During the course of these visits to his home, T. and his family decide that the effects of being separated from his family must be addressed. Loneliness is the prime effect of their forced separation. His wife feels overburdened with the added responsibilities of being the sole wage earner and family decision maker. After one year on dialysis, a joint family decision is made to relocate to the city. Once this fact is made known, the physical process of obtaining accommodations is actively pursued by both the South East Resource Development Council, (SERDC) and Medical Services Branch, (MSB).

Obtaining "a place to live", becomes T.s' main focus. Many hours are spent searching the classified newspaper advertisements, following up on "Apartment to Rent" signs displayed in the windows where vacant apartments are available, and

inquiring into housing recommendations from friends, MSB and SERDC. It was determined that the construction company where T. had been previously employed only offered short term disability benefits. His wife, because of the decision to relocate, had to terminate her part-time employment position. These two factors combined with his illness, forced T. to seek financial assistance from the Provincial Social Assistance Program.

As a client on the Social Assistance Program, T. and his family were allotted a monthly allowance to be spent on accommodation, food and living expences. They soon discovered that they were unable to locate a clean, warm place to live along with providing enough living space for his family within the constraints of the allowable monthly allowance. As T. still suffered from loss of energy because of his illness, he found climbing stairs extremely difficult. This fact further restricted the search for suitable accommodations. He and his family were also introduced to the subtle form of racism. When responding to "For Rent" ads in person, they were told that the apartment had been already rented. They also discovered that they had to have references before the landlord would allow them to rent the apartment. T. advised prospective landlords to contact his former employer in order that he could vouch safe for T.s' credibility. Finally, a first floor, two bedroom apartment was found. Although it was not considered large enough for their family, T. decided to take that particular apartment in order that he and his family could be together.

Although T. located the apartment independent of any agencies' help, he and his family appreciated the support which was given to them by the workers at the

SERDC. These individuals not only showed very real concern for the current plight of his family and their situation but they also worked diligently to make the family's adjustment to urban living less stressful. T. and his family were comforted to know that some of the SERDC workers, who were originally from their home area and knew many people in common, had an acute sense of the challenges that face relocated individuals.

MSB financially assisted T. and his family with the move to the city. Now that T. had relocated to the city, he and his family were considered the "responsibility" of the Provincial Government, not the Federal Government. T. had to again learn to live by a new set of rules. His wife and his children, who were under 18 years of age and were unemployed, were told that they had to apply to the City Welfare Department for their social benefits. They would receive these benefits for a ninety day period and if they were unable to find work after that time, they also would "go on Provincial Welfare".

Not long after T. and his family moved into their apartment, it became apparent that this accommodation was not suitable or safe for his family. Noise and the constant flow of visitors to and from some of the adjoining apartments woke T. and his family several times during the night. T.s' wife discovered cockroaches in her cupboards and a nest of mice had taken up residence in the bottom drawer of the stove. The children were afraid to go out in the evening and remained in the close confines of the crowded apartment. T. discovered, by speaking with some acquaintances, that he could place his name on waiting lists for housing accomodations funded by the city and Native organizations. The waiting list was long, but he felt that he should apply as soon as

possible. In the meantime, another apartment had to be located. Again the process was repeated and more suitable accommodations were obtained.

TRANSPLANT WAITING LIST:

T. was aware that his name was on the Transplant Waiting List. The possibility of obtaining a transplant with it's perceived freedom from dialysis was T.s greatest hope for the future. He saw his daily life as one where he would be in constant preparation for the call that a transplant was available for him. This meant not gaining weight and being compliant to the medical staffs' clinical instructions. His immediate family had all agreed to be tested to see if they would possibly be good matches for donating their kidneys to T. They realized that by giving their kidneys to T. they would be giving him a gift and a release from the life that his illness now forced him to live. Unfortunately, the one individual who was the most closely matched, had health problems which indicated that they would have been unable to function with the use of only one kidney. T. was reluctant to have anyone he knew donate a kidney to him. He had the fear that the kidney that the surgeons would remove might be the healthier of the two kidneys. He believed that in the future the remaining kidney might become diseased and that the individual would have to experience what he was presently undergoing. He did not want that responsibility. This fact forced T. to wait for some unknown individual, whose tissue and blood typing closely matched his, to die in order that he could have their kidney. The "waiting" became a frustrating task - never knowing when the call would come that a kidney was available for him. Somehow he and his family learned to function within their day to day life and to travel to the hospital every second day for

his dialysis. Underlying the performance of these functions was the constant hope that a kidney would soon be found. Finally, T. is contacted with the news that they have a possible donor for him. He arrives at the hospital full of apprehension and excitement. Further tests indicate that this particular donor would not be suitable. Disappointment preoccupies the family thoughts. Several months later, another call is given to T. and on this occasion, the match looks hopeful. T. and his family prepare for the impending surgery.

TRANSPLANT SURGERY:

T's immediate and extended family rally around him prior to and following his transplant surgery. There is little said by his family in the way of words but T. is aware of their thoughts and support for his recovery. T. now realizes that his next battle is with his own body rejecting his new kidney. There are signs of rejection soon after his surgery but he has been told that everyone experiences some form of rejection. This fact is dealt with by using very powerful medications. He realizes that if his new kidney fails, he must return to dialysis or he will die within a matter of days. After ten days in the hospital, he is finally judged well enough to return home. This occasion is a cause for a quiet celebration for both T. and his family. They realize that policy dictates that neither the donors name nor their familys' address can be supplied to them. Both T. and his wife wish that this rule did not apply as they would "just like to thank them" and to tell the family how they have "received extra life from the donation of the kidney". They believed that if the donors' family knew how appreciative they were, that somehow it might make the family feel that some benefit came from the persons' death.

After one year of his life being regimented by dialysis, T. finds freedom and a semblance of normalacy with his new kidney. The discipline with which T. had to live his pre transplant life is supplanted with a new set of rules. The results of blood tests and urinalyses dictate the amount and dosage of a myrad number of medications which he must now consume. His body weight must be constantly monitored as he realizes that one of the side effects of his prednisone medication causes excessive weight gain. Six months following his transplant surgery, he resigns himself to the fact that as long as he has his transplanted kidney he must be under close medical supervision. This includes monthly visits to the Transplant Clinic and referrals to several other medical specialists, such as a cardiologist and an ophthomologist. He sees these requirements as a "small price to pay" for being unleashed from the dialysis machine.

DECISION TO RETURN HOME:

After a year post-transplant, T. and his family are given the medical clearance to return to their home community if they so desire. The decision as to return "home" is not as easy as he and his family initially thought it would be. During the two years that they lived in the city, his wife had managed to obtain a part-time job and two of his children were well established in their schooling. When he and his wife discussed the possibility of returning to their home community, they thought of the easier life they now experienced in the city with its' conveniences and its' close proximity to medical care. It was finally decided that they would return to their home and they prepared for the move. Again MSB arranged for the moving costs, this time in order to return to the Reserve.

T. and his family were welcomed back into their community. During his two year absence from the Reserve, the people maintained contact with T. through telephone conversations and visits to his city home. Messages and current news were often relayed to T. and he was aware of the support from the people within his home community. He often thought that in his absence, he was not forgotten by his people.

T.s' transplanted kidney is functioning well but he must remain under very close medical supervision. He and his wife return to the city every four to six weeks to attend the Transplant Clinic. He sometimes finds it difficult obtaining transportation to and from his medical appointments whether it is to the urban centre or to the hospital near his home community. During the spring and winter months, sudden storms dictate his travelling schedules. Because of the remoteness of his community, he and his wife find it difficult to always obtain the proper foods, such as fresh fruits and vegetables, that should be included in his daily diet. T. notices that he is gaining excessive weight and finds it difficult to control this weight gain.

T. realizes that all the long term effects of transplantation are not completely determined or fully understood - his future is unknown. His illness has dramatically changed his life and the lives of his family. He has resigned himself to the fact that he must function within its' confines and to make adjustments to all the real and possible tasks of his illness.

CHAPTER V: OBSERVATIONS UPON THE IMPACT OF ESRD

The hypothetical case study will now be used to elicit the areas in which interventions and impact have occurred within the actual study group. This will be accomplished by using interpretive blocks of observational data. For the purposes of this presentation, the act of intervention will be interpreted as that which comes "... in or between so as to hinder or modify" (Morris 1982:686). By illustrating these interventions, one can begin to understand both the positive and negative impact that this illness and the subsequent relocation has on both the patient and the family.

The major interventions have been identified from the data and will be discussed under the headings of: The Illness Itself; Relocation; The Transplant Waiting List and The Transplant Surgery; and The Decision to Return Home.

"THE ILLNESS ITSELF":

Prior to any major chronic illness, an individual unconsciously declares a benchmark from which they measure what they consider to be their normal, everyday "good health". Once that individual develops a chronic illness, e.g. ESRD, their health takes on a new meaning and is gauged either positively or negatively against the previous standard. ESRD, along with its' symptoms and concomitant effects, act as the first intervention on this group of individuals.

As with Patient T. most of the patients interviewed had, at one point in their lives, experienced a time when they were "feeling well". Some of the patients had not

experienced "a sick day in their life" until they were diagnosed with kidney failure. For others in the group, diabetes and glomerulonephritis were the primary diagnoses. Since both these illnesses require medical intervention, these patients would generally have had some previous extensive contact with the health care system.

The psycho-social effects which occur to patients who have experienced a chronic form of illness and who have been immediately propelled into the health care system can be devastating. The individual experiences multiple losses within their lifestyle with the assignment of a new role -that of patient. The most significant role loss among the patients interviewed was with their perceived loss of identity through unemployment. All the patients had become unemployed as a direct result of their illness. The women in the group, who worked inside the home, expressed a lessening in their ability to perform their former role. This decrease in activity is due to the effects of the disease which may be exhibited by one or several of the following areas: loss of energy, the shortness of breath, the amount of time given over to the dialysis treatments and its' side effects. Although it had been many years since some of these patients had been employed, they couched their remarks in the form of dating various episodes in their life as, "before I got sick ... when I was working."

The patients told of the loss of independence which had been prominent in their earlier lifestyle.

One man had been a trucker, "hauling" for various companies. Now the complications of his illness required him to travel by means of a wheelchair, waiting for one of the wheelchair transportation companies to call for him at an appointed time. If this means of transportation was not available, he was forced to rely on family members to take him shopping or driving "to see the sights."

He spoke of how busy his family members were with matters in their own lives and how he did not like to "bother" them with his need to be transported to various places. For this individual whose livelihood depended on driving, this loss of independence was potentially traumatic. In this case, the patient asserted an alternative independence. He arranged for transportation on his own in order to prevent dependence on his family whom he viewed as being very busy.

The uncertainty of the illness, the loss of roles and the dependence on others is heightened when the patient is placed on the dialysis machine. The act of being placed on the machine in order that their life may continue is viewed by the patient as a further form of intervention and dependence. In contrast, the health care staff are taught to view this period in the patients' medical career as one of independence. In the Self Care Dialysis Unit, some patients are encouraged to collect their supplies, learn about their treatment, insert their own needles, and clean the machine upon completion of the treatment. With the CAPD method of dialysis, once the patient is "trained," they are viewed as "doing it [the treatment] on their own," with periodic clinic visits to ascertain clinical results.

During the interviews with post-transplant patients, their time on dialysis, is not viewed as a time of independence but rather a time of dependence. This independence-dependence conflict regarding renal patients is reflected in a "double bind" dilemma. "The patient must be compliant with the demands of the medical process but otherwise is expected to lead a normal life" (Blodgett 1981-1982:100). One patient in the study group described being on dialysis as being "chained to a peg". Metaphorically, this patient envisioned the machine as the peg and the leads to the access sites as the chains. This visionary transference is common among patients who rely on a machine for the continuation of their life. Another post transplant patient spoke of the feeling of being

"released", once he had his transplant. "It was like loosening a leash that you were locked to ... You don't have to reschedule your life [post -transplant] in order to fit your dialysis treatments into your life".

The stress and the uncertainty experienced by the patient also affects the family but in their case it is experienced from an outsiders perspective. It has been explained by family members of chronically ill patients that they "stand by" and appear to view the patients' illness and its' effects as if they were "looking through a glass" (Perry 1991). The family is not only affected by the interventions and dependence, such as the loss of employment, but they are also influenced by the psycho-social changes which the illness and subsequent treatment bring to the patient. The effects of these changes may be reflected in the patient as they present themselves in a different way from how they are perceived within their family situation. Although this dual presentation of self is a common phenomenon, one must be aware that a public face is the one which is most often on display during the treatment and clinical intervention. A wife of one of the post transplant patients spoke to me of her husband as being "so cranky." During the three interviews which were conducted with this individual, he presented himself as a humorous, thoughtful and even tempered individual. Within the confine of the family, the patient may feel comfortable to release their emotions and the frustrations of their illness. This spouse, witnessed how her husband presented himself to me and verbalized the incongruity of his "public" and "private" behavior.

RELOCATION:

The presence of the immediate family is also reflected in the decision whether to relocate to the urban centre in order to be in close proximity during the patients' treatment.

Once the individuals in the study group were told that they were to undergo dialysis treatments, accommodations in the urban area were taken, using a variety of methods. These included: a) Those who came from their home community and stayed in a medical boarding home/hostel for the duration of their dialysis treatment or until they were trained on the CAPD method. While on dialysis these individuals would return to their home community for short time periods (3-4 days). b) Those individuals who initially stayed in a medical boarding home and after several months "found a place" [to live] in the city. c) Those individuals who came to the city and stayed with friends/family and after several months "found a place" [to live] independently. d) Those individuals who came directly to the city and "found a place" [to live] within the city.

For those individuals who initially lived in the medical boarding homes, arrangements were made through the MSB. The patient may express their preference as to which home in which they wished to stay. This type of accommodation was viewed by the patients as one where there was "no problem" with staying there but that they were "bored" and that there was a lack of privacy. One patient stated that she "found the time

"long" as she did not know any people living in the city nor had she met any other dialysis patients in the boarding home.

The one patient who stayed in a hospital affiliated hostel while receiving his dialysis, returned home every week-end via bus. This patient recalls how sick he would feel after his dialysis.

He would return to his home where he would be warmly received by his family. He would be taken out to various activities, such as bingo (which they normally did not attend) and rodeos, "just so that he could see people." His family bought a fish tank in order that he could watch the fish and hear the water. The patient stated that it was very difficult to make the return trip to Winnipeg for his week of dialysis. He stated that he felt sick while he was in Winnipeg but when he returned home he felt better. This patient found the hostel accommodation "O.K." and was glad not to have to go outside to attend his treatment appointments (referring to a network of underground tunnels leading from the hostel to various areas of the hospital).

At present, these methods of accommodation appear to be meeting the needs of the patients who were interviewed in this study. Given the short time period and transitory nature of their stay, the response of "no problems" might be anticipated. If patients were to be on dialysis for a longer time or their time in the medical boarding home was not punctuated with visits "home," a different set of responses may have been offered. Given the transitory nature of the patients' stay in these homes, it would appear to be difficult to build any relationships with other patients. Relationships with staff members would possibly be an exception. Living in these accommodations on a long term basis and the added burden of the patients' illness may not prove to be a satisfactory arrangement. A possible solution to this dilemma is in the planning stages.

One of the patients and his family made the choice of not moving to Winnipeg. They lived a two hour drive from the city and the patient travelled home on the weekends. The decision to have the family remain at their home was influenced by the fact that their child was completing her schooling and they believed that the move to Winnipeg would be detrimental to her education. They also stated that although there were many Native people in Winnipeg, "they were not our people." As a result, of the concern for their child's education and their desire to be among their own people, the patient commuted for approximately eight months for his treatments. In this case, the travel distance was not prohibitive and the patient could return to his family every five days. Two other patients attempted to drive into the city three times a week for their treatments. These patients had to drive for one and a half hours and for forty-five minutes respectively each way, three times a week. This travel time, accompanied by the four to five hours on the dialysis machine, left these patients exhausted. One patient stated that he found this means of travel to be very difficult especially during the winter months. It was during that time that he made the decision to relocate to the city.

For the majority of the individuals in this study group, once the decision to relocate to the city had been made, the patients' interaction with the agencies was both heightened (as seen with the relocation services provided by MSB) and/or involved a new group of institutions employing a different set of expectations. Although there are organizations, eg. MSB and SERDC which aid the patient in finding accommodations, MSB was the only group cited by this study group who either attempted to and/or located housing for the individuals. The majority of the patients found "a place on

my/our own." The method of locating their accommodation was generally accomplished by: using the advice of others, e.g. dialysis doctors; friends/family; newspaper advertisements; and driving and walking around the streets in the core area looking for "Vacancy" advertisements in the windows of apartments. The timing of relocation usually coincided with the period when the individual was just beginning their dialysis treatments. For one patient this was a very difficult time for her. She stated, "I was so sick and then to have to drive around on a bus looking for a place ..." compounded her problems.

The most common adjectives used when the patients were asked what they were looking for in their accommodations were the terms: clean, warm, safe and close to their medical appointments. For most of these patients, these amenities were not found in their first accommodation following relocation. For some, it meant several moves within the city in order to locate more acceptable living conditions.

Since these patients were all unemployed, either prior to or as a direct result of their illness, they had to receive financial assistance from the Provincial Welfare Department. Reliance on this service provides additional interventions into their lives. These included restrictions upon the amount of money a patient is allowed to spend for their accommodation. As a result, many of the patients stated they were unable to find acceptable housing with their Provincial Welfare Allowance. These rates are set as guidelines but one patient was not aware of this ruling. This matter was explained in the following manner.

A young post transplant patient, who had her child living with her, was only able to afford one bedroom apartments and she always ensured that her daughter "had the bedroom" while she slept on the couch in the living-room. She stated that she was unable to locate a suitable two bedroom apartment for the rate which was allotted to her by the Social Welfare Department. She stated that the apartments which she would have preferred to rent (for reasons of cleanliness, warmth and safety) were twenty-five dollars (\$25.00), above the rates provided by the Social Welfare Department. As a result of obtaining unsuitable housing, this patient and her child moved several times in search of a clean, warm, safe place to live.

The spouse of another patient told of the first place they lived in when they came to the city as being totally unacceptable from her previous living conditions.

She described the apartment as dirty and infested with mice and cockroaches. There was no refrigerator or stove and the landlord kept promising that he would have these appliances delivered but they never materialized. When the family were able to locate more suitable housing on their own, the landlord refused to return their damage deposit.

Other patients complained of the noise in their apartment block and of undesirable neighbors. They verbalized these two factors in terms of both annoyance and safety of their families.

Although there were negative impacts on the individual patient relocating to the city, positive experiences and adjustments were also discussed.

One patient, who decided to relocate to the city because of the energy and time expended in travelling to and from his dialysis treatments, moved alone into an urban apartment. He spoke of the subsequent difficulty which he experienced in budgeting for his food. In his other place of residence, family members purchased and prepared his food. He stated that he had to make "adjustments" as to how and what he had to spend his money on. He said that "it took awhile" but with the help of "some other people" he was able to "get the hang of it."

Several patients stated that they would not return to their home community to live now that they have experienced life in the city. They responded with phrases such as: "Why should I go back to ..., there is no electricity and no running water?" "There is nothing much to do there." "I have an easier life now living in the city."

The major positive impact for this group was seen in the accessibility to education either for their children, their spouses or for themselves. While one patient and her husband lived in the city, for her nine years on dialysis and post -transplant, her husband was able to complete training for an occupational trade. When they decided to return to their northern community, her husband acquired a "good job" because of his training, whereas previous to their relocation, he had been unemployed. Several of the patients were involved in "upgrading" courses. Their individual pride was readily evident when they spoke of the different subjects that they were taking and their plans for future courses. Another patient stated that all her family had moved into the city because most of them had medical problems which required constant monitoring. She stated that since her family was in the city, she did not have any reason to return to her home community. One patient laughed when she talked about how her children accepted the families' decision to relocate. She stated that when her family was living in the city, her children wanted to return to their northern home. Once they returned to their home community, the children wanted to move back to the city.

There is apparent confusion as to which agency or institution is responsible for the delivery of goods and services essential to the Native dialysis patient. Since the

major interventions at this particular time in the patients' medical career are institutional, a brief description of the patients' perception of their services will be addressed.

A patient from the study group explained that when he and his wife first arrived in Winnipeg to relocate, a person from MSB showed them the available housing in Winnipeg. The patient found none of these places acceptable. As he plainly stated "they were all dumps." He decided to look for a place by himself, rented an apartment near a member of his family, and personally paid for the damage deposit and the first months' rent. He then stated that it was Social Services that called to ask if he wanted to look for a place. When questioned further, it was determined that it was MSB that phoned to repeat their request to be of aid in locating a place to live. A representative of MSB asked the patient who had paid for the damage deposit and the rent. The patient responded that he had done so. The patient believed that the representative of MSB "didn't like that." The patient stated that MSB did not refund the damage deposit but paid for the rent from that time period until he and his wife returned to their community.

The patients' recollections on this particular issue were validated with his response to a similar question asked in a previous study (Renal Disease Study: 1989). As was noted in the preceding text, the patient confused the two agencies during the telling of the incident. Since the patient was no longer the responsibility of MSB, once the patient relocated, this event may suggest that it was the Provincial Social Service agency that was interacting with this patient.

One of the patients in this study group, who receives provincial assistance, had difficulty obtaining transportation to the Clinic. This fact could have either resulted from lack of finances through improper budgeting (on the part of the patient) or failure to consider (on the part of the agency) that the patient required extra medical transportation costs. I arrived on three separate occasions to interview this patient for the second time and each time she would be classified by the staff as DNA (Did Not Arrive). I was told by one of the staff that sometimes the patient was unable to keep her appointment because she did not have the money for her bus fare.

A patient summarized his thoughts on the delivery of the various services for Native people. He stated that some people, who did not know the proper places and the people to contact, "fell through the cracks." Three patients who were interviewed, told of "helping" people who, in the opinion of one individual, "needed help." To one of these individuals, help meant providing a broad range of services - from pushing a car to visiting Native individuals and providing emotional, cultural and financial support. Another patient saw his role in a tenants' organization as a means of helping his fellow tenants with various problems related to the different social agencies. He recalled that, the evening before our conversation, a man in the apartment block had broken his eye glasses. The patient explained that he "was able to contact the right people" and that the man would be picking up his glasses that day. He also explained that people do not know "how to go about finding out about the different services that are provided in the city." He continued with the example of all the services provided by

the different transportation companies in the city. His knowledge had been gleaned from his experience in utilizing these services.

None of the patients in this study group had any contact with the Medical Interpreters' Program (MIP) from SERDC in regard to their move to the city. Challenges and issues pertaining to relocation were addressed during the informal interview and observation of SERDC.

Loneliness and dissociation, were issues addressed by the Medical Interpreters Program (MIP). These issues were evident among the patients when they either spoke of leaving their home community and/or their family in order to have their dialysis treatments. As was stated earlier in the presentation, one patient returned to his home on the weekends in order to be with his family. He spoke about how he did not feel well during the five days in Winnipeg for his dialysis but felt better when he returned home with his family on the weekends. The patient is not the only individual who suffers from loneliness. The individuals (in this case, the patients' wife and family) who must remain in the home community are also very lonely. It was noted while interviewing a dialysis patient for the ESRD Relocation Impact Study that loneliness for the family was a very real issue.

This patient had been in the city for four years receiving dialysis, returning to her remote northern community every six weeks to be with her family for a stay of 3-4 days, financed by MSB. The patients' husband who works in the northern community was visiting the patient and was present during her dialysis treatment and subsequent interview. The patient explained that this was only the second time in four years that her husband was able to visit her in the city. His job responsibilities and the expense of the extended trip made frequent visits impossible. Both the husband and wife spoke emotionally of the loneliness they both experienced as part of this forced separation. They wondered why an

apartment could not be found in one of the areas serviced by the Local Centres where they "could be together" and the husband could maintain his current employment. Further discussion regarding this case revealed that this patient was seen as non-compliant in regard to her treatment and therefore not a "good candidate" for a Local Centre. At present, the patient has been allowed to have her dialysis treatments close to her community with her compliance closely monitored.

Loneliness for the sense of "home" was evident when the spouse of one of the study groups' patients was asked what it was like to return to their home community following her husbands' dialysis and post transplant recovery. Her face broke into a smile and she said, "It's great being back home! - "I was free."

Several factors may have contributed to the ability of these patients to find accommodations "on their own" and, therefore, to have had relatively limited experience with the organizations. All these patients spoke English which would aid in the communication of their needs and requirements for their act of relocation. The spouse of one transplant patient stated, when asked about their move to the city, "we were lucky because we could speak English." There were also varying degrees of sophistication with the services which these agencies provided. Some of these patients, were either previously employed or lived in communities in the southern area of the province. These patients, previous to their relocation, had access to the urban areas and this was seen as a positive point for locating housing "on their own". Although relocation was stated not to be a problem for one transplant patient, he stated that he could understand it being a problem for some people coming into the city from more remote communities. He believed that "some people don't know the proper channels to go through." He continued by stating that since it was just he and his wife that had to

relocate, they did not experience the problems that larger families would encounter. He also believed that having a family member already living in the city was helpful.

Other comments and concerns regarding housing and agencies were collected while the researcher was waiting in the Clinic waiting area and from recollections of another health care professional. One such comment was made from a recently transplanted Native individual who moved from his community to the city with his young family. He stated that it was difficult to find housing because "you don't have references." The patient, in this case was referring to the references that must be supplied to prospective landlords before obtaining accommodation within the city. Having newly arrived in the city, he was unable to supply proof of being a "good tenant."

Another case was related by a health care professional of a dialysis patient who is familiar to the researcher and who experienced "a very difficult time" when she first relocated. The patient did not speak or comprehend English and had no understanding of how to obtain any type of aid. The health care professional related that this person did not have a change of clothing when she first arrived for dialysis and through advocacy on the part of several individuals was able to receive the proper services.

It was clearly evident in all the interviews conducted with the representatives of the agencies that these individuals were sensitive to the issues related to Native relocated patients. One representative, when asked what he found, in his experience, to be the effects of relocation stated:

... how depressed the patients appeared to be because of the move to the city. Loneliness was also a problem and the stress of waiting for a kidney transplant.

He stated that he has seen some patients "destroyed" because of the dependence of their illness.

Other representatives told of observing the loneliness that relocated patients experience especially when they do not have their family members with them in the city.

A Native representative spoke of services that were provided for Native dialysis patients as being different from non-Native patients. She recalled that some:

Patients returned from dialysis treatment and stated that the person in the next bed to them during their treatment received, for example, tickets to some event, e.g. to a hockey game. These patients stated that they were not offered these tickets. The representative speculated that the dialysis staff may feel that that particular patient was not interested in a ticket or that the patient did not make it known that they would be interested in a ticket. The representative also stated that they know of services which are provided by such groups as the Kidney Foundation, Homemakers etc. to non-Native dialysis patients that are not provided to Native patients. This observation may be due, in part, to the thought that Native patients are the Federal governments' responsibility and therefore these extra services are provided by the proper government agency.

Other representatives spoke with empathy when they told of the difficulties that some Native relocated patients experience, especially without the use of the English language. Moving to strange and unfamiliar surroundings during a time when they are attempting to cope with the difficulty of their illness was also viewed as a challenge for some of the patients.

The awareness of the challenges which confront all dialysis and transplant patients are observed in the formation of the team approach to the patient's overall care. Members of the various disciplines, e.g. Nephrology, Social Work, Dietetics etc. are involved in the patient's care.

The publication of The Kidney Disease Foundations' Manual, "Living with Kidney Disease" is viewed by both staff and patients to be a positive step in patient and family education. The next stage, as noted by some health care professionals, is to have this manual translated into some of the Native languages.

The amount and degree of the patients' involvement in each of the agencies depends on various factors. These factors would include: their classification of treaty status; their place of residence; their economic conditions; their degree of sophistication with agencies; their personal decision making; and their support network of family and/or friends.

The patient who is classified as a Status Native (as defined by Indian and Northern Affairs Canada INAC), has a treaty number and lives on a Reserve and decides not to relocate, will receive benefits from the MSB.

The patient who is unable to economically provide goods and services for themselves and/or their family will be eligible for Provincial Social Assistance. Depending on the size of their family, their personal income and/or savings, and their dietary requirements, social assistance will be provided for these patients.

The patient who has had previous experience and/or knows of individuals who have had encounters with these groups will be aware of the services which they provide.

The patient, along with their family, must be the individuals to make the decision whether or not to relocate. If these individuals decide to move, depending on their

treaty status and place of residence, the patient and/or family will be eligible for benefits from the agencies which have been previously discussed.

The patients' decision to relocate must take into consideration the effects of that move on the family as a group. Having friends and family, either in the city or phoning and offering support, such as by providing accommodation or emotional support, are factors which are considered beneficial to the patient.

Not all Native patients request the benefits of these agencies. An elderly patients' response during a previous study on the topic of relocation speaks of independence. This dialysis patient answered in the following manner when asked if agencies helped him.

No, but I did not need them. I suppose they would have helped me if I tried, but I didn't need them. Generally, I am on my own all the time. I tried to help myself. I suppose I was taught to fen (sic) for myself (Kaufert et al Unpublished:1989).

This response may be a characteristic reply indicative of this individuals' age group and his previous solitary lifestyle of hunting and trapping. This individual, because of his age would also have the financial benefit of his Old Age Security and Supplemental payments.

In summary, the patients within the study group, all had some form of contact with these agencies, except with SERDC, and all to varying degrees. They moved through the different organizations at different times and had different experiences with each of the organizations. The contextual nature of their involvement was different for each individual patient, each family member and for each health care worker. This

contextualization, as Weidman describes, is "The process of understanding every component of a unit in which health care is provided and then tracing a patients movement through that system, into the home and community and back again for the next visit" (Weidman 1982:218).

THE TRANSPLANT WAITING LIST AND SURGERY:

Biding ones time for any type of event, means feelings of expectation and for some, fear of the unknown. For a dialysis patient who has had to relocate with family members, the act of being placed on the Transplant Waiting List may be viewed as the first hope for escape, both from the constraints of dialysis and as the freedom to return to their home community. For some of these individuals "getting a transplant" becomes their main focus and goal in their life.

Once the patient is placed on the waiting list, a mixture of feelings evolve. These include a combination of stress, uncertainty, frustration, and hope. The thought that one must either wait for a family member to offer to donate their kidney or for some unknown individual to die in order that the patient may have their kidney constantly intrudes into the patients' thoughts.

For the individual on the waiting list, a telephone call may be received which will indicate hope that a "match" is found only to be told that they must again wait. One such patient recalled being contacted when a possible kidney transplant was to be available for him.

He stated that at that stage of his disease he could not afford to have a phone in his home as neither he nor his wife could work (his wife stayed home "to look

"after" him). As a result, a member of the Royal Canadian Mounted Police arrived at his home on the Reserve and asked to speak to him. The patient said he lifted his head from the couch where he was resting and asked the police officer what he had done wrong. The officer replied that he was sent to tell the patient that there was a possible kidney for him in Winnipeg and that the Transplant team were unable to reach him with the news. The patient came to Winnipeg the next day to find out that the kidney was not a "good match". Within the week, a compatible kidney was found and he received his current transplant.

This story (retold on two separate occasions) not only evokes the feelings that this individual experienced while waiting for and receiving a suitable kidney but it also tells of the wider issues of his disease and its' effects. As the listener to this story, we can sense how the patients' illness affected the quality of his life, how the authority of the police officers' presence affected his response and how important it is, once a possible donor is found, to have the patient notified.

Once the transplant surgery has occurred, the patient soon realizes that a new type of dependence and a new form of intervention begins to occur. For the post-transplant patient, the dependence on a machine is supplanted by another type of dependence. The new kidney now replaces the machine as the "peg". The myriad number of medications and close clinical supervision and control are the new "chains" which help ward off the possibility of their new kidney being rejected by their own immune system.

The uncertainty of not understanding the full impact of how their transplantation will affect their future health is a further consideration for these individuals. They witness the importance that the medical staff place on their post -transplant Clinic visits, their monthly checkups, innumerable blood and urine tests along with the resultant

coordination of their medications. The fear of kidney rejection interferes with their feelings of becoming free of their former life on dialysis. To be free, for some individuals, means the independence to make the decisions to return to their home community or to become employed or to make a life for their families which they view as more acceptable from "being on welfare". Rejection of their kidney can mean a rejection of their hopes for their future.

THE DECISION TO RETURN HOME:

Once the post-transplant patient is given the medical clearance to return home, the previous process of decision making must be repeated - only on this occasion they must ask, do they return home or do they stay in the city? The effects of this decision must be weighed. For some individuals, the thought of "returning home" is foremost in their thoughts throughout their illness but when the actual time to make that decision occurs other thoughts and realities intercede.

As was observed in this study group, most of the patients preferred to remain in the city post transplant. Their reasons for their decision were very pragmatic. These purposes were for education, a perceived easier life with the amenities of running water and electricity, and the presence of other family members in the city.

If the conclusion is made to return home, a reentry phase must be undergone. This includes adjusting oneself to their former lifestyle and to the changes, (social and family) which have occurred in their absence. Other interventions occur which make the decision to return home a difficult one. These interventions include dietary; access

to medical facilities; transportation; inadequate living conditions - risk of infection; and lack of social agency support services.

Because of the remoteness of some of the northern communities, foods such as fruits and vegetables are not readily available. Not only do the patients gain weight from the effects of their prednisone medication but they also become obese from eating an imbalanced diet chosen from a limited selection of foods.

Because of the remoteness of some of the northern communities, the ability to quickly obtain access to the relevant medical personnel and facilities is problematic. Since transplant medicine is an interrelated discipline, all of its' effects and idiosyncrasies can not be expected to be known by community medical staff. Some of the post-transplant patients' medical concerns are not of a nature that can be dealt with at a community level, therefore further intervention must occur. Therefore, obtaining the proper medical advice; recommending medications that do not interact with the transplant medication regime; and obtaining blood work must be coordinated with the urban Transplant Clinic team.

Essential to the overall care of the patient is the importance of patient follow-up within their community. This can be accomplished by having the community health care workers interact and appraise the urban health care staff of the barriers and problems which the remote northern patient experiences.

Closely linked to the problems of medical access is the difficulty of transporting individuals to and from their appointments. The uncertainty of the weather; the

seasonability of landing an aircraft or the accessibility to the community year round, affect how and when the patient will obtain medical intervention or receive their cyclosporin medications. There is also the difficulty in transporting blood samples to the laboratory in the larger centre. This longer than average time lapse from when the sample is drawn to when it is analyzed, affects the results of the testing and in turn would influence the dosages of their immunosuppressive medications.

In some of the communities, water supply and sewage disposal are inadequate and for some, a vehicle for disease. Proper personal hygiene is difficult when water has to be carried or drawn from a common standing pipe and taken to a house which is cold, and without electricity. One of the patients in the study group related the unsuitability of her northern home. She explained that it had no basement but rather was "built on a slab." It was too crowded for her four teenage children and the problem of the inability to shut all the doors in the house because of the lack of door handles. The result of these inadequacies, according to the patient was an extremely cold house. She spoke of requesting a note from her Transplant Clinic doctor to bring to the Band Chief, stating that the doors must be repaired as it was affecting her health.

Because of the remoteness of some of the northern communities and their small population bases, the social agencies which are evident in the southern urban areas are not able to be supported. Northern communities such as Thompson and Churchill, act as centres for some agency support. As a result, the patients in the remote communities must rely on either family - or neighbor-based social networks for their support. One patient from a northern community spoke about how, on her previous Clinic visit, the

doctors ascertained some kidney rejection symptoms. As a result, she and her husband who had accompanied her, had to stay in the city while she underwent further diagnostic tests. The trip which was to have taken two days now took two weeks. She stated that her children "managed" back home by having "the older ones looking after the younger ones" and with the added help of a neighbor who "looked after" her children.

The previously discussed interventions which occurred in this study groups' lives represented both a hindrance and a modification from their former healthy state. Other than the involvement of MSB, the rural/remote, relocated Native dialysis patient, interacts with similar agencies as would their non-Native counterpart. Services which are provided for the patients are attempts at producing the best possible care for the patient and their families. What complicates this care is the fact that these individuals must relocate to be in close proximity to these facilities. This means leaving places and people that the patient/family consider important at a time when these factors are of utmost significance. Many of these individuals come from areas with high unemployment rates, therefore necessitating financial assistance from local and outside agencies. Along with the high rates of unemployment experienced on many of the Reserves, comes the socioeconomic effects of poverty, eg. limited access to housing; water and sewage; proper nutrition and education. For some individuals, an inability to speak or understand the English and/or medical language complicates and adds to the overall challenge of coping with the chronicity of ESRD.

It can be anticipated that given the disease-specific interventions compounded with the effects of poverty, rural place of residence, dislocation, absence of an under-

standing of the English language, and the frustration of their chronic illness, the impact on the patient/family of relocated ESRD Native patients has the potential of being a devastating experience.

CHAPTER VI: CONCLUSIONS

The Grounded Theory method provided a set of strategies which have been employed in the collection and interpretation of the data for this presentation. Concepts have emerged from the data and have been subsequently triangulated with data related to the same phenomena "... but deriving from different phases of the fieldwork, different points in the activity within the setting, or the accounts of other participants in the setting" (Long 1984:97). Triangulation has been developed for this particular study where observational data was collected from the health care system; the supporting organizations; and the patients/families. Investigative triangulation was also employed through the researchers participant observation of both the Dialysis Support Group and the Dial A Life Housing Program. Because of the complexity of both the public and private accounts obtained from these sources, the areas of variables, biases and validation pertaining to these groups must be addressed before any conclusions are attempted.

VARIABLES, BIASES AND VALIDATION RELATED TO STUDY:

VARIABLES AND BIASES: It is assumed that with the increase in the numbers of comparisons or triangulations within ones data, the confidence of the research findings should also increase (Long 1984:97). Although triangulation methods have been employed, there are several factors which have influenced and prejudiced the data obtained from this study group.

- a) The patients who have been interviewed for this study are the survivors of a larger

group of Native patients with kidney disease. They have endured through their dialysis career, been chosen for transplantation and survived in order to be interviewed.

b) These patients have, because of their place of residence, been required to relocate to an area which provides the type of care necessary to maintain their life. Without this act of relocation, some of the interventions would not have occurred and therefore not been present to affect the patient/family. Thereby selecting this group of patients with the inherent interventions on their lives and on those of their families will imply that some form of either hindrance and/or modification will result.

c) Given that the patients have been selected from two transplant groups, (1985 and 1988), the patients and their families have undergone their dialysis and relocation experience at varying times. For example, one patient began their experience ten years previous to the interview, while another patient had begun their experience two and one half years before the interview. The patients/families recall of facts pertinent to their act of relocation will be tempered with time along with changes in the treatment modality and method of follow-up.

d) The patients'/families' trajectories will also differ. How the patient perceives treatment and the impact of the treatment will be viewed and reported differently by the patient, family member, health care worker and organizational worker.

e) The study group size is small, making external validity difficult.

f) The patient/family may view their relocation experience as positive if they have obtained opportunities on which they may place a positive value, eg. education. Conversely, the opportunities of poor and inadequate housing may evoke a negative opinion towards relocation.

- g) The context in which these interviews were undertaken and recorded were not optimal. The constant activity and interruptions which occurred within the interviewing sites were not conducive to sustained conversation. The lack of privacy and the fact that health care givers were in close proximity may have influenced the responses of some of the patients and family members.
- h) Patients also may have been concerned over their current test results and/or diagnostic tests e.g. biopsies and therefore answering questions regarding their past life may not have appeared important.
- i) All the patients within the study group spoke English. This fact would provide easier access to information and communication within the health care system and support agencies than if they spoke only a Native language. This fact alleviated the interpreting role of the Native Medical Interpreter, although the interpreter would visit and offer assistance to Native patients who would have been admitted to an urban hospital.
- j) The patients had varying degrees of sophistication within the urban setting. This was obtained during a prior time, either through employment, acquiring an education and/or visiting friends/family. This practical experience was evident when a family contacted and subsequently settled a dispute with their landlord by utilizing the services of the Provincial Ombudsman. When asked who it was that recommended this action, the patients' spouse said that she did not remember.
- k) Three of the patients were considered "helpers." At the time of the interview, these individuals were able, using their past life and illness experiences, to assist other individuals who required information and guidance. These "helpers" appeared to be viewing their present life from their past experiences. They spoke in terms of how they

currently manage other people's problems. When questioned about their own relocation experience, they used terms such as "it was hard", and "I had to make adjustments."

l) The supportive agencies described in this presentation are not exhaustive. An example of other agencies are Ma Maw Wi Chi Itata, Native Home Finders, and the Indian Family Centre. Concentration on these agencies could have elicited a different set of concerns and/or solutions to the impact of relocation.

VALIDATION: Given these variables and biases and the restrictions of both the size and availability of the study group, the validity of this presentation was attained in the following manner.

a) Since the patients were interviewed on either two or three separate occasions, overlapping validation was attempted. This was accomplished by using two methods of questioning. The first was referring to phrases or groups of thoughts which were raised in the preceding interview sessions and then rephrasing the questions for the subsequent interviews. The second method was asking either the spouse/family member or the patient a similar question on an individual bases. For example, one spouse told the interviewer that he had a job. When, on a separate occasion, a question which referred to the patients' spouses' job was attempted, the interviewer was told that her spouse "was not working." During another interview, the interviewer was able to ascertain via conversation, that the spouse would be attending occupational upgrading and would therefore be attending a technical school. The concept of whether "school" was classified as employment was inconsistent between the spouse and patient.

b) As was previously discussed, a patients' recollection regarding their involvement

with agencies e.g. MSB and SAP was validated with his response from a previous study.

- c) Validation was also achieved and utilized by investigative triangulation where interviews were obtained from members of the various agencies and from participant observation in both the Support Group and the Dial A Life Housing Group.
- d) Copies of the researchers' transcribed notes were given to representatives of the MLCDP and SERDC for validation of the information which was obtained from the previous interviews. Feedback was received and utilized to correct and/or expand the existing information. Clarification questions were addressed to the other representatives and overlapping validation was carried out between all interacting agencies.

RECOMMENDATIONS AND FUTURE STUDIES:

In the process of developing this presentation, a number of issues which cross cut its "Purpose" have emerged. Some of these concerns were identified by the health care staff, patients, and community agency staff and communicated to the researcher. The responses to all these matters would be beneficial to the overall care of the ESRD patient. These will be briefly discussed.

- a) Following an interview session, the researcher was approached by a patient and spouse to intervene in their difficulty with the water supply on their Reserve. They perceived that the "chemicals" which had been identified in their water sample were detrimental to the patients renal condition. They not only saw the negative effects of the physical ingestion of the water but also in its' absorption through bathing. This concern was also recorded through conversation with other Native individuals. This case was pursued by the researcher, by contacting the government agencies responsible

for providing water and sewage facilities to the Reserves. The patient's request provides two areas where researchers could offer beneficial assistance. These are in the areas of examining the complaints of the poor water quality and to record the patients' explanatory model of their illness perception. The latter issue could produce significant insights into the patient's understanding of their illness.

b) The methods and principles of informing Native patients of the prevention and impact of chronic diseases should be addressed. One diabetic ESRD patient told of attending the diabetic education classes in one of the city's hospitals. He believed that the information given to the Native patients regarding diabetes ..."went in one ear and out the other." He suggested that the educational information be of a more visual nature. He explained that Native diabetic people be shown a circle and that diabetes, as a concept, would be in the center of that circle. The illness of diabetes would stay in the center of the circle if you took your pills and followed your diet. If you did not adhere to these things then you would move outside the circle and other things would happen to you, e.g. poor eyesight, amputation etc. The patient suggested ..."you can even have some one like me there who has had an amputation and show them what can happen to you if you don't stay within the circle."

c) It has been observed that there is a low number of Native kidney donors compared to the numbers of Native individuals who require kidney transplantations. One method of addressing this imbalance is providing the relevant information in a culturally appropriate medium, eg. a video. Once this has been accomplished, it is hoped that informed decisions can be attempted on the part of Native individuals. The subsequent results of this form of education should be evaluated as to its' present and future

effectiveness as an educational tool.

d) Treatment compliance, particular to Native patients, has been identified as an area in which the clinical staff would like to have a better understanding. It has also been identified that some patients arrive in the urban area and do not understand why they are there. A Native physician, carried out a survey at one of the medical boarding homes, by asking the patients the reasons why they were in Winnipeg and staying in a boarding home. She discovered that most of the patients did not understand why they were in Winnipeg for treatment or tests and/or why these tests or treatments were necessary. This communication breakdown must be addressed at both the community and the urban health care treatment levels. Determining a method of informing the patient at the community level would provide a means of relaying information and in turn create a more positive healing and compliant atmosphere for both the patient and their family.

e) The patients' compliance as to medication, particularly the young, post transplant patient, is also an important area to understand. For some patients, dramatic changes in their "body image" or physical appearance, may be an indirect cause for non-compliance behavior regarding the taking of medications. This occurs as a direct result to either their dialysis treatment and/or the effects of their immunosuppressive medication.

f) It is also important to understand what the patients' families comprehend about the illness. Their perceived peripheral role should be addressed with the realization that this role plays an important part in the patient's overall care and quality of life.

g) An attempt must be made to understand whether the impact experienced by the

Native ESRD patient is similar to, greater than or less than the impact upon the non-Native ESRD patient. This would influence the types of services and information given to Native patients.

h) It has been recorded that a patient requested help from her transplant physician in alleviating her undesirable living conditions in her home community. She asked that he write a letter to the Band Chief stating that given her medical condition (as a post kidney transplant patient) her housing be upgraded and/or repaired in order that she may not suffer from the consequences of a cold and drafty house. Documentation of requests such as this, demonstrate how the health care worker must be concerned with the clinical aspect of the patient's illness and also with the broader socio-cultural context.

i) A greater understanding is required of the difficulties that the post-transplant patients face re- entering their remote home communities. For some individuals, the lack of the required dietary foods; the absence of electricity, proper water and sewage facilities; and the prohibitive travel to and from medical appointments and facilities affect the patients' treatment compliance and their general well being. The first step in understanding the complete impact of relocation on the Native ESRD patient/family would be the documentation of their return to, and resettlement within, their remote home community.

CONCLUSIONS:

POSITIVE VS NEGATIVE IMPACT: The impact which results from the act of relocation is instrumental in drawing two different but interrelated conclusions in

regard to the observational data. Firstly, its' negative impact and secondly its' positive impact. The negative impact revolves around the illness itself, the physical act of relocation, and some of the aspects of their transplantation. The positive impact has been derived from these negative effects.

For most of the individuals in the study group, their illness provided the opportunity to come to the urban center. Once in the urban environment, the effects of education, an easier lifestyle and the presence of other family members added to the degree of positiveness with which the patient/family viewed their relocation experience. This is not to say that there were not very real negative impacts for these individuals, e.g. poor and inadequate housing, but retrospectively, these individuals saw their experiences in a positive light. For those patients who did return to their home community post-transplant, the positive effects of education and subsequent employment were viewed as taking the results of their relocation experience and applying the effect (eg. job training) to their home community. For those other individuals who returned to their home community post transplant and for those who had chosen not to relocate, the sense of home community was very strong. They had other obligations, eg. (child's education); did not "like" the city; and lacked the freedom they experienced in their previous lifestyle. In retrospect, these individuals experienced more of an impact because of the negative interventions than those patients/families whose perceptions focused upon the positive impacts of their relocation.

The only agencies which were involved with this group of patients were the required services of both the MSB and Social Allowance Program. The MSB involve-

ment included provision of transportation, accommodation, return visits to the home community, and the relocation costs of both moving to the urban centre and the return relocation to their home community. The Social Allowance Program provided the financial assistance for their goods and services once the MSB benefits had expired.

Some individuals have suggested that these services, particular to the Native patient, are beneficial. They concede that for some Native people, the move to the city because of the patients' illness; an inability to speak English and their unfamiliarity with both the urban and health care setting makes their adjustment to their illness more stressful and in turn more problematic. But underlining these challenges, lies the opinion that because these ESRD patients are Native, more services are provided for them than for non-Native ESRD patients. Given the fact that both the MSB and the Social Allowances Program are both bureaucracies, operated by rules and regulations, it is only reasonable to assume that some individuals and/or their particular case will not "fit" the organizations' criteria. It appears to be those individuals who, as a patient stated, "fall through the cracks" that are the ones who are most seriously deprived of their goods, services and quality of life. Since the Native ESRD patient must interact with an agency which has been developed to look after their needs, the risks of falling through the cracks are greater. Whether the negative impacts are greater than for the non-Native ESRD patients and therefore a cause for an ethnicity argument, remains for another study.

The data from this study support the conclusion that each Native patient must be viewed as an individual entity and not as a collection 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. These methods of adjustments and survival are evident in this study group and are expressed on an individual and idiosyncratic bases. The members of this study group were and continue to be, presented with the constraints of their illness. They have chosen to accommodate to these constraints by using their own particular methods of adjustment. In undertaking this adjustment, they are reacting to both the positive and negative impacts by attaining a way of balancing their lives and the role their illness and its' impact plays in it. Despite all of their problems, or perhaps because of them, they had "... acquired a depth, a fullness, a richness and awareness of [themselves] and of the nature of things of a rare sort, only to be achieved through experience and suffering" (Sacks 1983:241).

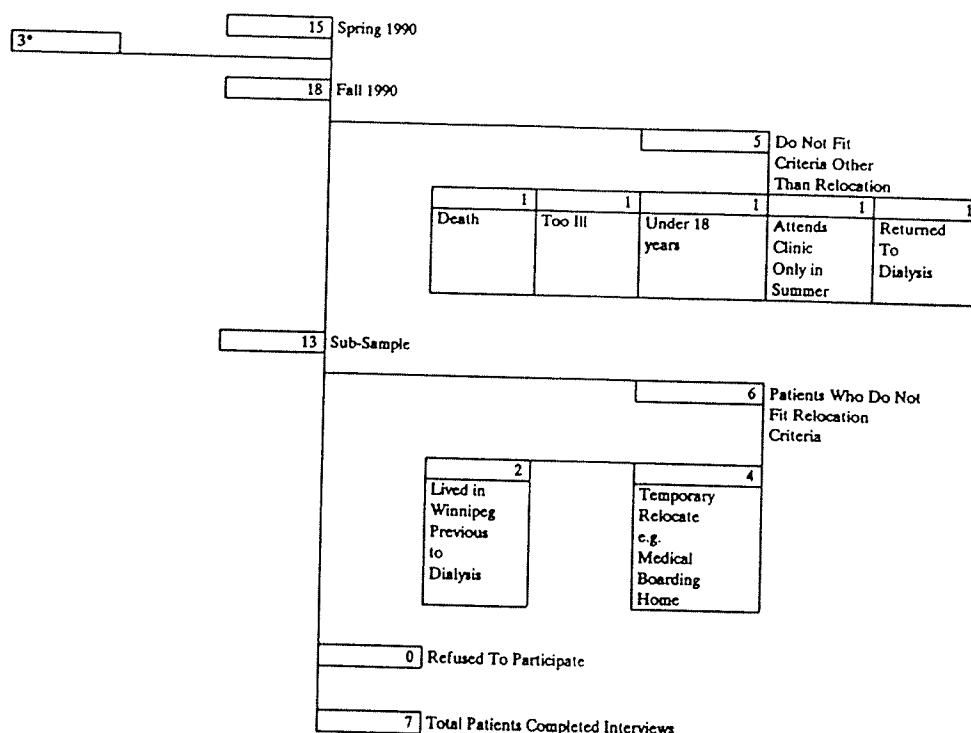
The significance of this research has been argued from several different, but interrelated, perspectives. From the literature on the high incidence/prevalence of diabetes mellitus among the Southwest Native groups, and the apparently similar demographic and risk patterns that are emerging for Canadian Natives, it follows that diabetes mellitus will be increasing in its' prevalence/incidence among Canadian Natives. In time, with this increase in the numbers of Natives with diabetes, diabetic nephropathy and perhaps, cardiovascular disease will also increase. With phenotypic amplification, the prevalence and incidence of ESRD should also increase. Additional arguments, dealing with alcohol/drug abuse, streptococcal infections, poor social conditions and higher than average mortality and morbidity rates, support and amplify the argument that the increased threat of ESRD is genuine.

The numbers of new ESRD patients in the general population are increasing. For the Native ESRD patient, the case load is and will continue to expand and therefore it can only be expected to be a significant issue for the future. The act of relocating ESRD patients has been shown to be problematic, given this present trendline it can only be expected that this too will become even a greater problem for the future. This research has implications for the present, short term questions dealing with ESRD and relocation but is equally important in longer term perspective. The results of this study can add to the knowledge essential for planning, development, and allocation of the present and future health care resources.

The necessity of projecting the future needs of the health care system is imperative. For the Native people, the economic and social costs are reflected in the society as a whole. To attempt to understand the process of relocation and the apparent impact on the patient and family of the ESRD patient makes this project a worthwhile and notable one for future decisions in the area of the health care delivery system and most importantly for the Native people.

FIGURES

PATIENT PARTICIPATION



*3 Additional Patients Accounted for From Two Separately Supplied Patient Lists
 Fall 1990 - Current Listing at Time of Data Collection

Figure 1

INTERVENTIONS - ABORIGINAL KIDNEY TRANSPLANT PATIENTS

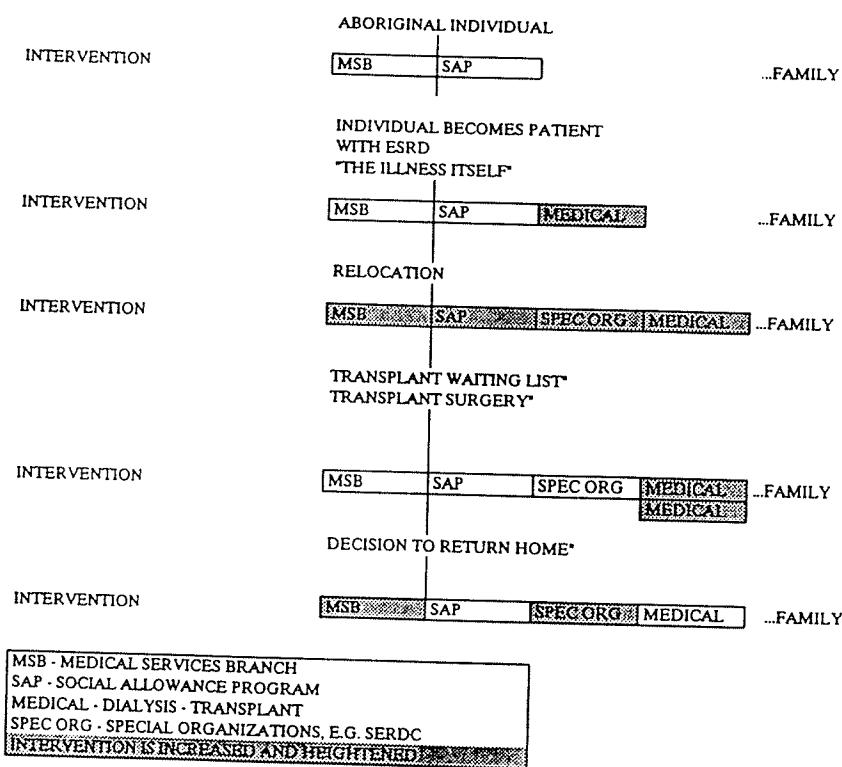


Figure 2

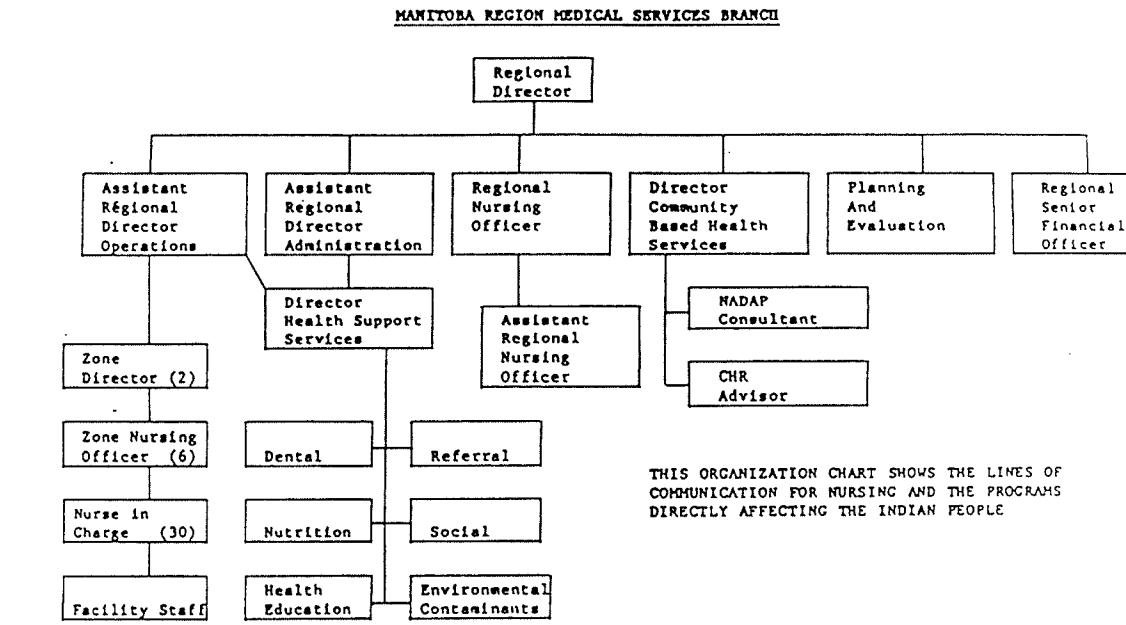


Figure 3

Introduction to Medical Services Branch

TABLES

TABLE I

Manitoba Renal Transplant Registry

YEAR*	N
1976	2
1977	1
1978	2
1979	0
1980	1
1981	2
1982	0
1983	3
1984	4
1985	8
1986	6
1987	4
1988	7
1989	8
1990	3

N = 51

Nurse Supplied List of Native Patients

YEAR*	N
1971	1
1975	1
1976	2
1977	1
1978	2
1979	0
1980	2
1981	2
1982	0
1983	3
1984	4
1985	8
1986	6
1987	4
1988	7
1989	8
1990	3

N = 54

* Year depicts current year of transplant.

Table II

AGE - SEX 1985 - 1988 TRANSPLANTED NATIVE PATIENTS

TX PATIENT	SEX	1985	BIRTH/YEAR
1	F		1963
2	F		1951
3	F		1945
4	F		1927
5	M		1948
6	M		1940
7	M		1938
8	M		1934

TX PATIENT	SEX	1988	BIRTH/YEAR
1	F		1961
2	F		1959
3	F		1949
4	F		1977
5	M		1936
6	M		1933
7	M		1923

APPENDIX I

INFORMATION FORM FOR PARTICIPATION IN THE RESEARCH PROGRAM: THE IMPACT OF URBAN RELOCATION ON NATIVE KIDNEY TRANSPLANT PATIENTS AND THEIR FAMILIES: A RETROSPECTIVE STUDY

It has been indicated through research that Native Manitobans are at an increased risk of developing kidney failure. In order that appropriate treatment, i.e. dialysis and transplantation is realized, Native Manitoban kidney patients living in rural and/or remote communities must relocate to be near the available treatment facilities. The change in the patients place of residence combined with the experiences of the kidney disease has diverse effects on both the patient and their family. The purpose of this study is to document, through biographical case histories, the patients and/or families past accounts of their adjustment to an urban setting.

This study will consist of a series of interviews with post kidney transplant patients, their families, and health care workers. These interviews will include questions documenting the experiences of having to relocate from the rural/remote community.

Representatives of agencies, i.e. Medical Services Branch, Health and Welfare Canada; Manitoba Family Services; South East Tribal Council and medical boarding homes, will be interviewed only as a means of obtaining description of the facilities and programs which influence Native Manitoban kidney patients and family relocation experience. These agency interviews are only intended to obtain an overall description of the relocation process and case-specific information will not be discussed.

This study will require a review of your medical records. This review is to interpret your relocation within the context of your medical problems and treatment history. I therefore request permission to contact your attending physician to review your medical records. This information along with the interview information will be recorded using a number and will not be linked with your clinical record or influence your treatment. If, through this review of your medical record and/or interview sessions, information is obtained that requires additional medical attention, a referral will be made to the appropriate health professional.

Language interpretation services will be provided if you wish to complete this interview in the language of your choice. These interviews will be tape recorded. You will be given the opportunity to refuse to have this method used as a means of recording the interview.

By consenting to be interviewed in this study, you have the right to refuse to answer any question or to withdraw from the study at any time. All the information obtained in this study will be kept confidential and will not be associated with you publicly. This information will not affect the quality of your present and/or future medical care.

I thank you for your interest in this study and I will answer any questions which you might have regarding this project.

Sincerely,

Joan Mollins
Graduate Student
Medical Anthropology
University of Manitoba

CONSENT FORM FOR PARTICIPANTS IN THE RESEARCH PROGRAM:**THE IMPACT OF URBAN RELOCATION ON NATIVE KIDNEY TRANSPLANT PATIENTS AND THEIR FAMILIES: A RETROSPECTIVE CASE STUDY**

NAME.....

ADDRESS.....

If I am a participant in this study, I understand that it will involve interviews with my family and health care providers. These interviews will consist of questions pertaining to the experiences of relocation. I also understand that my medical records will be reviewed.

I understand that interviews will also be undertaken with representatives of the following agencies; Medical Services Branch, Health and Welfare Canada; Manitoba Family Services; South East Tribal Council and medical boarding homes. I understand that these agencies will be interviewed only as a means to obtain a description of the facilities and programs which I, as a relocated Native Manitoban kidney disease patient or my family must experience. These agency interviews are only intended to obtain an overall description of the relocation process and I understand that my patient case will not be discussed.

I understand that this interview will be tape recorded but that I have the right to refuse this method of recording the interview.

This study has been explained to me to my satisfaction in the language of my choice. I understand that I may refuse to enter this study or upon participating, refuse to answer any question and/or withdraw from the study at any time.

I agree to participate in the study entitled **THE IMPACT OF URBAN RELOCATION ON NATIVE KIDNEY TRANSPLANT PATIENTS AND THEIR FAMILIES: A RETROSPECTIVE CASE STUDY**. I understand that my participation involves a series of interviews with me about the experiences I encountered when I moved from my home community in order that I would receive medical treatment for my kidney disease.

Signature of Participant

Print Name

Date

Signature of Witness

Print Name

Date

Informed Consent and Ethical Procedures

The study proposal was approved by both the "Faculty Committee on the Use of Human Subjects in Research," University of Manitoba and the "Health Sciences Centre Adult Clinical Studies Impact" Committee.

The Information Form and the Informed Consent Form were offered to the patients once it was determined that the individual had to relocate. The patients were asked to read the forms and if there were any questions regarding their contents and/or the study in general, they would be addressed during their next Clinic visit. The time between the Clinic visits varied depending on the patients' physical condition. The majority of this group of patients returned every four weeks, some returned at two week intervals for various tests and/or physical examinations. Once the researcher determined their return visit, (by consulting the chart and appointment book) the researcher approached the patient after receiving permission from one of the Clinics' staff and asked if they had had the opportunity to read the Information Form. Eight (8) Information Forms / Informed Consent Forms were circulated, two (2) of which were mailed to the patients who would not be returning to the Clinic for an extended time period and the other six (6) forms were personally presented to the patients. Extra copies of these forms were always kept with the researcher as the patients did not bring the original copy to their return Clinic visit. Before the patient agreed to sign the consent form, they were invited to reread the form and they were assured that the present form was the duplicate of the form they had initially received. The Information Form was left with the patient. One of the two patients to whom the forms were mailed

did not return the signed consent. This was requested from the patient on three separate occasions without compliance. One patient spent most of the interview looking at the Consent Form and did not sign the Form until near the end of our conversation. This patient readily supplied information and appeared to be interested in the study.

The seven Consent Forms are placed in a separate file and will be kept in such a manner for one year following completion of this presentation. There are no data attached to or connected with these forms. The interview data is stored on four computer disks, two of which are backup copies. The data are entered, using the numbering system from Table II, eg. "1 (1985)". This number would include interview material from Transplant Patient 1; Sex, Female; Birth/Year 1963. The patients' name and demographic information is stored in a file on a separate computer disk.

The patients were not approached to be interviewed unless verbal consent was given by both the Clinic staff and the patient. This procedure was repeated each time the patient was interviewed. On one occasion, the researcher arrived at the Clinic to interview a patient for his 0800 appointment. At 0930, the patient called to tell the Clinic staff that he would be arriving for his appointment but that he was "so sick." When the Clinic staff relayed this message to me, I did not continue to wait for the patient to arrive as I believed that the purpose of my presence was not necessary given the circumstances of the situation. I checked with the staff later in the day and it was determined that the patient had been admitted to the hospital. Two days following his admission, I approached the Clinic staff to obtain permission to speak with the patient on another hospital unit. I explained that I would secure the consent of the staff on that

particular unit before approaching the patient. The Clinic staff, who were apprised of the patients' condition agreed. I proceeded to the other unit and again obtained permission and the patient was pointed out visiting another patient in a room across the hall from the nursing station. I approached the patient and explained the purpose of my visit and we returned to his own hospital room to continue our conversation. This conscious method of obtaining permission from the myriad number of patient gatekeepers requires time, determination and imagination. Not only is it imperative to build rapport with the patient before attempting an interview but within a medical bureaucracy, mutual trust must also be accomplished before these gatekeepers will allow doors to be opened in order that patient access may be granted.

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