

THE MEANING OF CARING FOR A CHILD WHO HAS RENAL FAILURE:  
A PHENOMENOLOGICAL STUDY OF  
URBAN ABORIGINAL CAREGIVERS

by

Nadja-Lynn Schulz

A thesis submitted to the University of Manitoba in partial fulfilment of  
the requirements  
for  
the degree Master of Nursing

March 21, 1996



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ISBN 0-612-16273-7

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A PHENOMENOLOGICAL STUDY OF URBAN ABORIGINAL CAREGIVERS**

**BY**

**NADJA-LYNN SCHULZ**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
of Manitoba in partial fulfillment of the requirements for the degree  
of  
MASTER OF NURSING**

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## ABSTRACT

An understanding of the meaning of Renal Failure (RF) to caregiver families and the meaning of the various therapies and treatment modalities required to sustain life is essential to efficient and appropriate nurse caring practices and systems, including decisions about health promotion, illness prevention and treatment. A phenomenological approach was used to explore the meaning of caring for a child who has RF from the perspective of urban Aboriginal family caregivers. The emergence and description of perceptions of urban Aboriginal caregivers satisfied a limitation in our existing knowledge base. Data were collected through interviews with 10 Aboriginal caregivers. These caregivers were caring for children who were out-patients at one urban tertiary care hospital, and who were being followed in the transplant clinic or the children's clinic. Eleven main themes were identified. These were; Discovering Renal Failure, Living in Fear, Managing the Illness, Relocation, Surviving, Building Strengths, The Role of the Family, Unmet Needs, Envisioning the Future, Enhancing Power and the Meaning of Health and Illness.

## ACKNOWLEDGEMENTS

There are many people who have contributed to my graduate education and whom I would like to acknowledge.

I would like to give my thanks to the caregivers who shared their most revealing and personal experiences with me.

I would like to thank my committee members. Dr. Patricia Farrell, chairperson, for her continued faith in me. Dr. Farrell's sensitive and insightful manner inspired me throughout my program of study. It was a privilege to have Dr. Farrell guide my thesis project.

Dr. David Gregory served as my internal committee member. I thank Dr. Gregory for contributing to my thesis study with his expertise in qualitative research and Aboriginal health. Dr. Gregory's helpful suggestions were appreciated throughout my thesis study.

I thank Dr. Malcolm Ogborn, external committee member, for his guidance, support and encouragement.

The support of the graduate students with whom I shared this experience is greatly appreciated and will always be remembered.

I would like to thank my husband Gerald, who supported me throughout my studies. His support and encouragement will always be appreciated.

I would like to thank my family. My children Kirsten (3) and David (Jesse) (6) for learning to become so independent and undemanding of my time. I am grateful to Judy and Ronn, my sister-in-law and brother-in-law, who have supported me throughout my studies by ensuring that my children always had an ample supply of movies to view and books to read. The times they spent with our children were appreciated. I thank my mother Lieselotte and my mother-in-law Susan who have never stopped supporting me and my family. I will always cherish the goodies that were bestowed upon our family to ensure that we were not hungry or lacking of anything! My father Leonid and my father-in-law Leonard, who were always supportive of my studies.

I would like to thank the Kidney Foundation, Manitoba Branch and also the Kidney Foundation of Canada for their support of my study. I would also like to thank the Canadian Association of Nephrology Nurses and Technicians for the support of my study through a bursary award.

## CHAPTER ONE

### Introduction and Background

Renal failure is the loss of kidney function which can progress to an irreversible and permanent condition known as Chronic renal failure. An understanding of the meaning of Renal failure (RF) to caregiver families and the meaning of the various therapies and treatment modalities required to sustain life is essential to efficient and appropriate nurse caring practices and systems. The purpose of this study was to describe the meaning attributed to the experience of Renal Failure by urban Aboriginal caregivers, and the impact of this illness on their every day lives.

### The Problem

Presently, the exact cause of many types of renal disease is not well understood. Kidney diseases which most commonly cause Chronic renal failure (CRF) include the following: glomerulonephritis, diabetes mellitus, polycystic kidney disease, pyelonephritis, urinary tract obstruction, and hypertension (Lancaster, 1984). Broyer, Donckerwolcke, and Brunner et al., (1981) reported statistics from eight of the largest European countries (as cited in Robitaille, 1990) while Potter, Larsen, Leumann et al., (1970); Fine, Malekzadeh, and Pennisi et al., (1978); DeShazo, Simmons, Bernstein et al., (1974); Arbus, De Maria, Galiwango, Irwin, and Churchill, (1980); and Robitaille, Mongeau, & Yazbeck et al., (1978) provided research from five large centers in North America which attributed glomerular diseases as the main cause of ESRD among children (as cited in Robitaille, 1990).

Chronic pyelonephritis and/or malformations of the urinary tract were reported second in importance. Robitaille (1990) cited that the incidence of specific hereditary renal diseases varied significantly according to geographic area and accounted for 11 % (Arbus, De Maria, Galiwango, Irwin, & Churchill, 1980) to 22 % (Robitaille, Mongeau, & Yazbeck et al., 1974; 1982). Renal hypoplasia and/or dysplasia is cited as the fourth most important cause of ESRD (Robitaille, 1990).

The proportion of CRF cases among Aboriginals, due to diabetes and glomerulonephritis, is higher than in all Canadians (Young, Kaufert, McKenzie, Hawkins, & O'Neil, 1989). It also seems that the kidneys of Canadian Aboriginals are more susceptible to pathology which results in end stage renal disease and malignant changes (Young et al., 1989).

Usually, renal failure starts slowly and progresses over a number of years. At the early stage of RF the only treatment needed may be a change in diet or some medications. In later (end-stage) RF, treatment with dialysis or renal transplantation will be necessary.

Once the kidneys are functioning at less than 10% of their normal rate, dialysis or transplantation is needed. Hemodialysis (HD) is a treatment whereby the blood is cleaned by slowly withdrawing it from the body and passing it through an artificial kidney by using a machine. Each HD treatment usually takes three to four hours and is performed three times a week (Kidney Foundation of Canada, 1990). Peritoneal dialysis (PD) is generally a home dialysis therapy. Continuous ambulatory peritoneal dialysis (CAPD) is a technique where the dialysate is drained from the

peritoneal cavity and fresh dialysate is instilled three to five times daily. Intermittent peritoneal dialysis (IPD) is an individualized schedule where exchanges are done during the daytime for approximately 4 to 8 hours, and overnight exchanges are from 8 to 12 hours (Lancaster, 1984).

Once individuals are told that they have CRF and require dialysis, a number of decisions have to be made regarding these treatments. The treatment modalities that are available include PD which can be learned within two weeks and which can be performed independently by the patient and family at home, or HD which can be performed on an inpatient basis at the Health Sciences Centre (HSC) in Winnipeg, Manitoba.

The treatment of individuals, groups and families in the management of chronic illness is not satisfied within the present cure oriented health care system (Lalonde, 1984). In the attempt to achieve control of the disability as opposed to cure, a new system is needed. The World Health Organization met in Alma-Ata, USSR, in 1978 at the International Health Conference. A declaration was issued which stated that primary health care is the system needed to achieve health for all by the year 2000 (Mahler, 1988).

The primary health care framework is a broad framework that has the ability to capture the full role of nursing practice. Primary health care is defined as:

Essential health care based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their

development in the spirit of self-reliance and self-determination. (Mahler, 1988, p. 348)

Nurses have always been a part of community health care and will remain the principle professional providers of health care services (Mardiros, 1987). Health promotion and delivery of health services specific to community needs are now being acknowledged as the responsibility of the community and its members (Mardiros, 1987). Aboriginals are taking responsibility for improving their health by decreasing dependence on non-Aboriginal help and technology. Primary health care is being emphasized, and nurses can foster this approach by providing education on self-care. Mardiros (1987) states that:

...Professionals serve as advocates, empowering individuals and communities so that they can understand the cause of illness, make informed decisions, and promote their own well-being and enable all to realize their potential as useful members of society. (p.23)

Gaining an understanding of Aboriginal caregivers' experiences is a necessary step in fulfilling the self-care agenda of primary health care. Knowledge of caregivers' experience will facilitate an understanding of their responses to chronic health events and resulting health needs (Munhall, 1994; Rittman, Northsea, Hausauer, Green, & Swanson, 1993). This understanding can then enhance the development of preventive measures (Flaherty & O'Brien, 1992) and treatment programs that respond to the human concerns of the patient and caregiver. Benner and Wrubel (1989) found that one of the most neglected areas in the study of chronic

illness was an understanding and conceptualization of the way people perceive and explain changes in their lives due to chronic illness.

## CHAPTER TWO

### Review of Literature

Some Canadian studies have explored the consequences of issues related to end stage renal disease (ESRD). These have examined the epidemiological, clinical, and sociocultural dimensions of ESRD in adults (Young et al., 1989). The reported "... 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, p. 756). Research on chronic disease in children has focused on family adaptation and coping mechanisms (Clubb, 1991; Copeland & Clements, 1993; Stullenbarger, Norris, Edgil & Prosser, 1987). The role of the environment has also been examined (Strauss & Munton, 1985; Turner-Henson, 1993), as has the impact on children having siblings with chronic illness (Davies, 1993; Loebig, 1990). None of the studies have focused on the perceptions of Urban Aboriginal caregivers caring for children with ESRD. Given the indication that the Aboriginals may be at a greater risk for developing ESRD, study in this area is important.

#### Epidemiological Studies

Young et al., (1989) reporting on the first phase of a multidisciplinary study examining the epidemiological, clinical, and sociocultural dimensions of end stage renal disease (ESRD) stated that Canadian natives [sic] are at a higher risk for ESRD than the Canadian population in general. In a Canadian study of mortality of residents

of reserves in seven provinces from 1977-1982, kidney diseases were not among the top ten ranked causes of death. However, for persons under 70, Aboriginal men had twice the risk and Aboriginal women had four times the risk of dying from kidney diseases as compared to Canadians nationally (Mao, Morrison, Semenciw, & Wigle, 1986). The extent and magnitude of kidney disease amongst Aboriginal peoples still needs to be assessed (Young et al., 1989).

### Studies on Chronic Disease

Research on the perceptions of caregivers of children with chronic disease is available, but research focusing on urban Aboriginal caregivers is notably missing. Clubb (1991) states that over the past three decades, a common theoretical approach in studies of parental reaction to a special child, is to use the theory of time-bound sorrow. This theory holds that there is a progression through a series of time-bound stages that eventually leads to the acceptance and adjustment of the parents to their child's condition. A challenge to this approach emerged in the early 1960's with a new theory called chronic sorrow. The chronic sorrow theory, which is not as well accepted, defines parental reaction as functional adaptation to, not acceptance of, the child's condition (Clubb, 1991).

The alternative theories of time-bound sorrow and chronic sorrow were compared in a study of 27 parents and 43 social workers to determine which theoretical process better described parental reaction (Wikler, 1981; Wikler, Wasow & Hatfield, 1981, 1983). Social workers were selected randomly from a social service agency and the parents were chosen nonrandomly from one clinic list. A 4-component

questionnaire was used as a measurement instrument. Neither the reliability or validity of the questionnaire were described. Several strategies were used to analyze the data. A total distress measure was used to quantify data on the degree of perceived happiness or sadness experienced at crisis points. Structured graphs were used to illustrate time-bound and chronic sorrow. Parents identified the graph closest to their experiences, and also sketched their own adjustment process graphs. The results supported a chronic sorrow model depicted by parents as a life of ups and downs. The findings from the social worker participants also supported this conclusion. Limitations of the study include possible bias in the results due to the non-randomized parent sample, small sample size, and lack of validity and reliability of the measurement tool.

A third model uses the theory of critical times to examine parents of chronically ill children. In a qualitative study using a questionnaire developed from data collected in a pilot study, Copeland and Clements (1993), examined the perceptions of nineteen parental dyads with a child who had diabetes, cystic fibrosis, or cancer. A two-page questionnaire based on the theory of critical times was developed from the pilot study and explored common themes across disease categories. This study compared strategies used to provide support during difficult times. When the strategies were compared, it was found that parental perceptions were similar but their responses to the situation were different. Limitations of the study included use of a questionnaire, which did not give in-depth data, and a small

sample population. It also did not ensure that the forms were completed individually by the mother and father since they were completed at their homes.

Both studies would have needed larger sample sizes in order to represent a variety of cultural backgrounds and to lend further weight to the findings. The findings from Wilker (1981) reflect support for the chronic sorrow theory. Although chronic sorrow is not specifically addressed by Copeland and Clements (1993), processes are identified that seem to correlate to descriptions of chronic sorrow. As noted by Clements, Copeland, and Loftus (1990), there are "specific ways of coping" that the family conforms to in order to meet their needs (p. 158). For my study, there was no literature available on the meaning of the experience from the perspectives of urban Aboriginal caregivers caring for children with renal failure, therefore the use of a theory for my investigation would have been premature.

In a descriptive study by Strauss and Munton (1985), 16 parents of developmentally delayed infants and toddlers were assessed during home visits. The purpose of the study was to identify the frustrations of the parents of developmentally delayed infants and toddlers. A brief interview using open-ended questions about parents' present and future concerns and support systems was conducted. The convenience sample included mainly professional, middle-class parents who could clearly articulate their children's needs and their own needs. The three major areas of concern were identified as grieving and depression, difficulties in obtaining adequate services for themselves and their children, and fear of the future. Limitations of this study were that no conceptual framework was used, the sample size was small,

nonrandomly selected and included only families that were well educated. In four of the interviews both the mother and father participated. In the remaining twelve interviews, only the mothers were interviewed. Research design, methodology, and data analysis were not described.

Many studies have relied on data obtained from mothers of children with chronic illness (Davies, 1993; Loebig, 1990; Turner-Henson, 1993). The assumption is that mothers are the primary caregivers of children. In a comparative study of nineteen mothers, Davies (1993) tried to determine if healthy siblings in families with a child with cystic fibrosis received less dependent care, as defined by Orem. Davies (1993) reported that the siblings of chronically ill children often perceived themselves as the forgotten member of the family, even though they did not receive less dependent care. This finding was based on data from the dependent care agent questionnaire which was new and without established reliability and construct validity. Sample size was small and homogenous, with only mothers included.

Loebig (1990), used an exploratory descriptive design to study the mothers' assessments of the impact of children with spina bifida on the family. Three questionnaires were used to collect data. One was the Impact on Family Scale by Stein and Riessmen (1980). This instrument had construct validity established. The tool's reliability, using alpha, was .88. The other two instruments were developed by the investigator and reliability was not established for one and not reported on for the other. Findings indicated that relationships within the nuclear family and the extended family were affected by having a child with a chronic condition.

A larger study done by Turner-Henson (1993), examined the role of the environment in supporting families with a chronically ill child. Using two existing data bases which included samples from 323 subjects, it specifically examined mothers' perceptions of the environment. The environment was assessed by the mothers as to how supportive, resourceful, safe and accessible it was. Only 5 of the subjects' children had renal disorders. This study demonstrated that environmental factors such as economic status, education, population density, resources, and employment opportunities play a crucial role in affecting family functioning. One limitation of the study was that there was no inclusion of support networks other than the mother.

In summary, although there were studies found on the caregivers of children with chronic illness, these studies for the most part, assumed a biological mother who was the primary, verbally articulate caregiver. Factors that may have influenced findings, such as beliefs, customs and values of the primary caregivers were not identified in any of the studies reviewed. Further, the meaning of the impact of caring for a child with a chronic illness such as RF was not described. No studies were found with a focus on the Aboriginal caregiver families, where the primary caregiver may or may not be the biological mother and where data collection strategies must be sensitive to the role of verbal behaviour in the study participant.

The patient and family's sense of well being and the patient's functional ability, including verbal behaviour, has been found to be increasingly important for nurses and other health care professionals to understand (Flaherty & Obrien, 1992;

Zhan, 1992). Culturally diverse nursing care offers a variety of ways to provide culturally appropriate care based on an individual's cultural values, beliefs, and practices including sensitivity to the environment from which the individual comes and may return (Leininger, 1985a). Nurses need to understand the meaning of the experience of living with RF as described by the patient and family in order to help patients live with their chronic illness (Rittman et al, 1993). Defining and measuring constructs such as quality of life in relation to health and illness continues to be a difficult task (Brink & Saunders, 1984; Tripp-Reimer & Saunders, 1984; Zhan, 1992). Munhall (1994) states that it is the perception of experience that matters not that which appears in reality to be contrary to, or more truthful than, that perception. If an individual perceives danger when there may not be any, in the reality of that person's lived experience, there actually is danger. The use of a priori theory to discover the meaning of caring for a child with RF from the perspectives of urban Aboriginal caregivers would likely not have revealed detailed descriptions of everyday life experiences. Hence the importance of and need for phenomenological approaches to the problem of interest.

From my review of the literature, it was evident that there is limited knowledge on the health beliefs of urban Aboriginal patients and families experiencing RF. Their knowledge, experiences, and the meaning given to these, have not been well documented, nor has the impact of the experience on family life.

### Purpose of the Study

The purpose of my study was to describe the everyday experience of urban Aboriginal caregivers of children with renal failure (RF). The following research objectives were proposed:

1. Describe the lived experience of urban Aboriginal caregivers of children with RF.
2. Identify the meanings, events, and circumstances of being a caregiver of a child with RF.

### Research Question

A phenomenological approach was used to explore the research question: "What is the meaning of caring for a child with kidney disease as described by the urban Aboriginal caregiver?"

### Theoretical definitions

For the purpose of my study, meaning was defined as the significance of the lived experience of the caregiver from the perspective of the caregiver (Avis, Gregg, & Scargill, 1963). According to Papper (1971), Renal Failure is "that stage of renal function in which the kidney is no longer able to maintain the integrity of the internal environment of the organism" (as cited in Lancaster, 1984, p. 2). For my study, Renal failure "RF" was defined as a chronic condition affecting the kidneys that persists and requires medical follow up for longer than one year. "Urban Aboriginal caregivers" was defined in my study as the primary caregivers who are registered as status or treaty Indians, non-status Indians, Metis (mixed Indian-white marriages)

(Young et al, 1989), or First Nations peoples'; have resided in an urban setting for longer than one year; or have had urban exposure for longer than one year; and looked after a child with RF. "Child" was defined as a person between 2 and 18 years of age who was the biological offspring of the parents or who had been the adoptive or foster child of the parents for at least one year (Loebig, 1990). This child was within the family unit for at least 6 months time.

## CHAPTER THREE

### Methodology

Qualitative methods are important approaches in research for developing knowledge (Boyd, 1990). For my study, I chose to use a phenomenological approach. Phenomenology differs from other types of qualitative research methods. Ethnography and grounded theory were two other qualitative methodologies that I had considered prior to this study (Table 1).

In my study, the goal was to describe the meaning of caring for a child with renal failure from the perspectives of the urban Aboriginal caregivers. Uncovering the knowledge surrounding the phenomena under study is achieved in phenomenology, by acknowledging human reality and how the individual perceives his or herself in the world (Boyd, 1990). One's perspective is therefore affected by one's own situation, personal history, and one's selection of various points of view.

The use of phenomenology requires a focus on the meaning of the experience as opposed to being concerned with the specific contents of experience (Boyd, 1990; Omery, 1983). In phenomenology, the participants are the co-researchers who help direct the interviews. Validation of the themes and relationships of information given are obtained during subsequent interviews with participants (Colaizzi, 1978). Lengthy and repeated interviews serve to facilitate descriptions of the participants' experiences (Giorgi, 1975). The aim of phenomenology is to describe, not to interpret the perceptions of the participants, nor to develop theory. Phenomenology has been used

to explore areas that previously have not been amenable to traditional methods of scientific research (Omery, 1983). For my study, the context in which the caregivers described their experiences was an important aspect to consider and is acknowledged within the phenomenological method (Boyd, 1983).

The goal of sampling in phenomenology is to obtain sufficient descriptions from participants about pure experience (Omery, 1983). Since the phenomena under study could only be described by those living through the experience, urban Aboriginal caregivers were the co-researchers in my study.

In phenomenology the information obtained is then used to guide further data gathering or sampling. Colaizzi (1978) stressed matching the source of the data with the appropriate method for collecting the data. For my study, semi - structured and informal interviews were used and the meaning of the experience was explored as it unfolded for the participants (Colaizzi, 1978; Omery, 1983).

In phenomenology, an extensive literature review is not done prior to the data collection as this would then necessitate more information that would need to be bracketed (Spiegelberg, 1976). Participants' experiences of the phenomenon are distinguished as being apart from their theoretical knowledge of it (Colaizzi, 1978).

In phenomenology, the researcher tries to take on the role of the research participants. This is accomplished by viewing actions from the participant's perspective "while standing back to ask questions about what the [participants] take for granted" (Bowers, 1987, p. 43). The intent is to describe the experience as the participants experience it (Colaizzi, 1978).

The data analysis procedures used in phenomenology are the coding of clusters of themes and subthemes. For my research, I chose to structure my study according to Van Manen's (1990) approach to hermeneutic phenomenological inquiry. A broad and systematic set of approaches were used to gain experiential descriptions from the participants. Van Manen (1990) refers to the initial draft of the data obtained as being the "protocol" (p. 63). Protocol writing in turn refers to the generation of initial texts from which the researcher can work. Thematic analysis is the examination of the commonly occurring themes which evolved from the experiential descriptions and which may be used to describe the meaning of the caregivers' experiences. As various themes are generated from the participants' experiences, phenomenologically sensitive paragraphs are then developed. These paragraphs are termed linguistic transformations. Follow-up conversations with participants serve to enhance the interpretation of the lived experience. The themes continue to serve as guides for writing.

The interview served primarily to gather the lived experience data, and to allow the participants to reflect conversationally to the topic (Van Manen, 1990). In my study I returned to the participants in order to dialogue about the context of the transcription of the interview (Van Manen, 1990). The philosophy of phenomenology is "open, interpretative, and individualistic" (Brink & Wood, 1989, p. 165). However, directions are given in the design which detail the steps to be taken during the discovery of the lived experience. These prescribed steps, on the surface, contradict the open philosophy of phenomenology. This apparent paradox is part of

the lived experience of this method and needs to be acknowledged and accepted. In practice, the experiences of the participants provided the direction that the research would take, thus reducing the paradox.

### Procedure and Study Setting

Following approval by the Ethical Review Committee at the Faculty of Nursing, University of Manitoba and approval for access to the Health Sciences Centre (HSC), participants for the study were selected from the clinic listings of children who receive health care services at the HSC Children's Hospital clinic and the Transplant unit. The HSC is a 1060 bed, tertiary care, university affiliated teaching hospital. Ethics protocols and procedures are detailed in Appendix A.

The Children's Hospital Renal Clinic was held every Wednesday from 09:00 to 17:30 hours. There were 749 patient visits recorded for the Renal Clinic from January to December 1994. There were one to two registered nurses in charge of the Renal Clinic. The number of children seen ranged from approximately 15 to 25 in total. On the Transplant Unit, the Children's Clinic was held every Tuesday morning from 09:00 to 12:00. Children may also be seen on other days if they are new to the program or if in need of attention. There were three nurses working in the Clinic. The usual number of children seen on a typical clinic day ranged from 4 to 10 in total.

Clinic nurses were requested to identify and approach potential participants. I was onsite at each of the Clinics during the initial data collection phase of the study. During the data collection at the Children's Hospital Renal Clinic, I waited in the

main patient waiting area. At the Transplant Unit, I used a separate waiting area, where the charts were kept, to wait for potential participants during the data collection. I interviewed participants at their homes during subsequent interviews, if possible, and if they agreed to this arrangement.

I met with the Nursing and Medical health care providers in the HSC Children's Hospital clinic and the Transplant unit, to explain my study and to answer any questions or concerns (Appendix B). The health care providers at the HSC were asked to identify participants who met the study criteria. The health care provider was then requested to ask permission to release the names of the selected potential participants to the researcher (Appendix C). I explained the study and either had the interested potential participants come to the designated interview room to sign the consent form, or thanked them for their time if they chose not to participate (Appendix D). Once in the interview room, the study was explained further and a written consent presented to the potential participants who were interested (Appendix E). The consenting participants were then asked to respond to the demographic questionnaire and be interviewed either at the clinic or another time was arranged at a place of convenience (eg. their home).

Realizing that the clinics can be extremely busy, I was on site at the clinics early to try and accommodate the participants. I also ensured that the other health care workers who needed to see the clients were given priority to meet with them. At times, interviews were interrupted by various health care workers wanting to see the

clients, seeking equipment, or looking for other clients. These health care workers consisted of clerks, doctors, dietitians and nurses.

### The Interview

In phenomenological research, participants are the primary source of data, and the investigator is the primary instrument. The participants described and interpreted the meaning of the events and circumstances surrounding their experiences of caring for a child with RF.

I began the interview with a brief explanation of its purpose, and the participants then completed a demographic questionnaire (Appendix F). Open-ended questions and probes were used to elicit data during the interview (Appendix G). Participants were asked to give an account of the meaning, for them, of experiences relating to caring for their child with RF.

The interviews were structured to encourage the participants to describe their feelings and experiences in their own words. Conversations were audio tape recorded to allow for accurate transcription of information given during the interviews. Participants were requested to be re-interviewed for validation of the data. For those individuals who wished, a telephone contact in addition to in-person interviews was used for brief validation discussions, to arrange visits and to provide a formal closure to the study.

The interview served primarily to gather the lived experience data, and to allow the participants to relate conversationally to the topic (Van Manen, 1990). An

example of this was that I inquired about the time that the participants first found out about their child having kidney problems and what this experience was like for them.

### Sampling

Participants that were (a) 18 years of age or more, (b) able to speak and understand English, (c) looking after an Aboriginal child that had been diagnosed with RF, (d) Aboriginal and have resided in an urban setting or had urban exposure for one year or longer, (e) willing to consent to participate in the study, who had experience with the phenomenon under study and could dialogue about their experiences, were included in my study (Colaizzi, 1978; Forrest, 1989). Sampling continued so as to meet the phenomenological content-method goal in the aim to obtain pure description. There is often a limited number of participants in phenomenological research due to the quantity and richness of data obtained (Jacobson, 1994). The sample size of ten which I obtained was consistent with the in-depth requirements of qualitative research such as phenomenology. It also fulfilled my aim to gain sufficient descriptions about the participants' pure experiences in order to fully understand and describe the research phenomenon.

Four of the participants had children that were being seen in the Children's Clinic. These children were being treated conservatively. Some children required consultation to specialty services, tests, medication, dietary interventions, or observation only. Six of the participants had children who were being followed in the Transplant Clinic. These children required various tests, consults, surgery, medication, dietary interventions, follow up, and observation.

The age range of the participants was 29 to 62 years; the mean age being 38 years. Three males and seven females made up the sample population studied. The education level of the participants ranged from grade three to eleven. One of the participants was retired and only one of the other participants were currently employed. Two of the participants left their jobs to relocate to the city due to their child's illness.

Four of the participants spoke Cree as their main language, and four spoke Island Lake dialect. One participant spoke Ojibway as their main language, and one spoke Saulteaux. None of the participants were born in Winnipeg. The number of years living in Winnipeg ranged from 0 years to 6 years. The number of years that participants had urban exposure ranged from one to 6 years.

The number of children that the participants cared for ranged from 2 children to 9 children; the average number of children being 4 children. Three of the children being cared for were foster children. One of these foster children was experiencing renal failure.

Six of the participants were caring for children who had renal transplants. This included interviews with two couples and interviews with two other caregivers. All four of the children who had transplants experienced maintenance dialysis. Four of the children being cared for were being treated conservatively.

Three of the participants had had no experience with others in their family that had RF, whereas the remainder of the participants did have others in their family with RF. The length of time of experience as a caregiver of a child with RF ranged from 2

months to 9 years. This time frame also reflected the number of years that follow up by health care professionals was necessary.

### Assessment

Each interview started with an assessment of the situation to ensure that the participant's child and/or children were comfortable and had their needs looked after. The younger children often coloured, looked at books, or lay upon the examination table. The older children would typically look through magazines or listen quietly to the interview. One mother held her child in front of her on her lap during the entire interview. In one interview, two children played pogs\* during the entire interview. Another child fell asleep on the examination table during an interview and began to snore.

### Setting the Pace

The traditional Aboriginal cultural beliefs and values that are related to health make it difficult for many to articulate these without context (Malloch, 1989). Aboriginals must relate holistically to a total way of life in which they are actively involved. There is no formal writing of traditional "Indian [sic] medicine" and values which relate to health (Malloch, 1989, p. 105). The information is passed down verbally through the generations of Elders. As I found in my interviews, there were

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\* Pogs is a game that is played with round discs having one plain side and one side printed with various logos or figures. In playing pogs, the participants use a larger disc called a slammer to aim at a stacked pile of discs in the attempt to overturn the discs to expose the printed side and therefore gain points or earn the opponents discs.

stories about the participants' lives and experiences that the caregivers told, in order to convey the meaning of caring for a child with renal failure.

The interviews ranged from 20 minutes to 3.5 hours in length. It was common to have frequent pauses and interruptions during the interviews. At times the pauses were to allow the participants time to respond to questions, or to attend to a child's needs. As described by Sorrell and Redmond (1995), silence may be used for keeping a comfortable pace throughout the interview, and for allowing participants to tell their stories in their own fashion. In the two dyads that were interviewed, the female participants initiated the signing of the consent form and also began to speak first in the interviews. The male caregivers spoke more than the female caregivers overall however the women always initiated the interview dialogue. In one interview the husband stated that his wife would have to validate his descriptions as "she would know more about that" and he did not recall or want to recall certain events. Interruptions included other individuals entering the examination room, or in the case of home interviews, visitors entering the home. Verbal consent was obtained during each subsequent interview and permission to re-interview the participants was established at each meeting.

#### Telephone Contact

Telephone contacts were made with individuals in six instances. Four of these instances included arranging times for interviews, and in two of these cases directions to a home was sought. In three instances I was unable to interview at a home residence. For two of these times the participants were not home, and there was no

phone in the household to arrange an interview. As mentioned previously, in one case an individual refused to participate without her spouse being present even though she had consented by phone prior to the meeting.

### Bracketing

Bracketing involved the suspension of what I thought I knew about the phenomena (Thibodeau, 1993) and then asking the participants about their perceptions of experiences they have had related to the phenomenon (Geissler, 1990). As Colaizzi (1978) argues, the phenomena must be understood by the researcher as people experience it. Since my clinical expertise is in nephrology, there was prior knowledge regarding my experiences that I needed to bracket.

The night before my initial interview, I spoke with the clinic nurse and one of the pediatric nephrologists by telephone regarding the start of my data collection the next day. From our conversations I had an idea that a large clinic of 20 children was scheduled and that accreditation would be going on. Based on this information I bracketed that the clinic would be a lot busier than usual. Prior to my first few interviews, I had also bracketed that the participants would be quiet, shy and guarded in their responses to my questions. I also did not anticipate any refusals to participate in the study. Prior to my first interview in the transplant clinic, I bracketed that participants would express concern over their child's physical appearance. However this concern did not arise until subsequent interviews with the caregivers.

Based on my previous interviews in the children's clinic, I felt that the health care professionals would be held in high regard by the participants. I also felt that a

return to "normal" as well as the desire to return to their home communities would be foremost in the minds of the participants that had been relocated to the city. Later, after having done a few interviews, I bracketed that parents in the transplant clinic would talk about the trials and tribulations that they've experienced during the time that their child had experienced RF. Surprisingly, little discussion regarding their previous experiences with a child on dialysis surfaced during the interviews.

Prior to one interview, it took the physician a long time to complete his examination and the ward clerk and nurses noted this as well. They stated: "I don't know what is taking him so long", "I wish he would hurry up already" and "you could have been in there already ages ago". The clinic nurses had identified potential participants in all of the other interviews, but in this instance the physician had decided to discuss my study with the family. While I waited, I found that my bracketing kept me calm and focused, as I thought that I would ask generalized questions and try to do less of the talking. This general view point paid off as I had a lengthy interview with two participants who offered me rich descriptions of their experiences of caring for a child with renal failure.

Bracketing became more personalized as the interviews progressed. The individuality of each caregiver was considered as I tried to bracket what a mother would consider to be important, what a grandparent would think about having a transplanted grandchild, or what a father would think about regarding his son's future life plans. In these instances, I felt that a mother would worry about the many trips required to return to the clinic, a grandfather would experience a lack of

understanding about renal failure, and that the father would express concern over repeated appointments at the transplant clinic, fear of worsening health and problems with compliance.

### Unusual Circumstances

Regardless of the business of the situation, I attempted to remain calm and to proceed with the interviews in various types of situations and settings. Once when the nurse told me that a participant agreed to be interviewed but would not stay after the scheduled clinic appointment, I went ahead and interviewed prior to the time that it took the patient to be seen by the physician. I told the participant that I understood that they could not wait, but would like to meet them and then perhaps we could meet again the next time that they came for the clinic, and she consented. At other times there were as many as five people in a small examination room, three of these being children under 6 years of age. I had knelt on the floor in order to proceed with the interview as there was a shortage of chairs. Prior to one home interview, I anticipated that the participants would be prepared with questions or concerns. I was surprised when I was greeted in a rather cool manner by the husband of the family who had not been informed of my planned visit by his wife.

There were two situations in which my presence would not be acknowledged by a family member. In the first instance, a spouse asked his wife to come and meet me when I suggested this after he had indicated who the individual in the kitchen was. After he asked his wife, he returned and did not mention her again in our conversation. Another time, a father kept himself busy in the kitchen and would not

come out of the room while I was there interviewing his wife in the adjacent living room. This lack of recognition may have been due to various reasons such as fear of challenges being made as to the knowledge of a family member, the lack of desire to meet a stranger, disapproval of having a researcher in the home, or, perhaps due to the Aboriginal cultural tradition of non-interference.

Another unusual event occurred in a clinic, when I had to offer my lap to use in order to sign the consent form. A couple of times also in clinic, I held the tape recorder during the entire interview as there was no appropriate place to put it.

I arranged to interview participants in their homes or another place if this was convenient. Four participants agreed to subsequent interviews in their homes and these were also the only individuals that had a home in the city. Two interviews were done using the native services unit manager's office at HSC.

The first interview that I did was in the native services unit manager's office. Prior to arriving with the participant, I had verified the use of the interview room with a native services worker. When I arrived with the participant and child, a native services worker spoke to the individual in her own language. This seemed to relax the atmosphere as the participant and the native services worker smiled and greeted one another then spoke a few words. For the next interview that I had, there was no interaction with a native services worker and the atmosphere seemed more tense, although there were other factors to consider. The child was very young and was wearing a urinary device for collecting a urine sample which the mother seemed worried about. They had also spent a long time in the clinic that morning and the

mother expressed that she was anxious about the trip home, since she hated to fly alone with her child. The remainder of the interviews were done in the children's or transplant clinics.

### Gaining Research Experience

The nervousness that I experienced during my initial interviews dissipated during subsequent meetings with the participants. Each participant offered a new challenge for me. I tried to meet all of the individuals without any preconceived ideas or opinions following my bracketing. At times I would bracket my thoughts by speaking into the tape recorder while driving down the highway enroute to the early morning interviews. When interviewing at the clinics, I chose to dress in skirts or dresses, trying to portray a neutral, casual appearance, wearing little makeup, no perfume and carrying my supplies in a travel bag. Although I did state that I was a nurse, I did not wish to affiliate myself with the other health care professionals on the units by wearing a lab coat, or my hospital identification card. I wished to put the participants at ease, so I refrained from wearing excessive makeup, styling my hair elaborately, or wearing expensive clothes. The participants seemed to feel comfortable with my appearance and did not hesitate to come with me when I took them to a private place for the interview. Initially, one caregiver was self-conscious about missing a front tooth, and tried to cover her mouth as she spoke with me. Later on in the interview, and during a subsequent interview, this participant appeared more comfortable and no longer attempted to conceal her mouth.

The home interviews seemed more relaxed and the conversations lasted longer than the clinic interviews in all but one instance. In this one case, the spouse of the participant would not come out of an adjacent room as long as I was there, thus I did not try to prolong the interview as I felt like I was intruding. In another situation where the spouse did not wish to meet me, I still felt comfortable with the participant and continued to dialogue with him. He later introduced me to some of his other family members. They entered the house unannounced, one granddaughter requested money from the participant and one son and his girlfriend had a drink from the fridge and then left. His son, seemed a little surprised to see me there and listened quietly without any questioning as I provided a brief explanation of my purpose for being there. The other two children did not pay any attention to my presence there. After the interview, this participant explained who's who from the many pictures located around the living room where we were seated.

### Validation of Findings

As various themes began to emerge, I began to envision ways of incorporating these into my interviews as a means of validating my findings. I typed out the various themes and used these to help me bracket my beliefs and I also gave these to my participants for discussion and validation during subsequent interviews. The participants did acknowledge that the themes were portraying their perceptions by referring back to them in conversation. For example one participant stated :

That time, when I had my son I never used to say anything like asking questions - the reason why. I never used to be like that. Like what I mean over here you had it, one of a, living in fear.

There appeared to be some difficulty with the medical language that was used. For example, a participant had difficulty describing the name of her child's illness: "It's poly, poly? ... for about that poly, poly ... disease." The participant that had an appointment with her child at the genetic clinic was unsure what this was all about. This caregiver asked me: "What is genetic?"

I would try to ask the participants if they understood what I was talking about or if I made sense to them intermittently throughout my interviews. During two separate interviews I was asked "Why you want to know about a question for that" and another time I was asked "What is the purpose of your research". For the first question I replied "Why I'm asking all the questions about this? and the caregiver stated "Yea", thus I then discussed the purpose of my study and did not probe as much for information during the rest of the interview, which went well. For the second participant, I gave a longer explanation of how I was trying to place myself in his shoes although I acknowledged that I could never do this. This response served to engage the participant in a lengthy interview in which many detailed descriptions were then given. The themes, which I had developed from the data, were discussed during the interviews and the words that I had used for my themes were then often repeated back during our conversations.

One male participant requested that I ask his wife for more details as she knew more about certain experiences. He also reminded me about asking his wife about my questions after she had left the room briefly and then returned. "Well, you can ask her, what she's thought about, what the last question that you told me."

### Intuiting

"Perceiving and intuiting" involves sensing and interpreting on a personal level in order to gain a larger sense of what meaning there is in what is perceived (Bevis & Watson, 1989, p. 288). By studying the perspectives of the participants, the essence of the experience can be "intuited or grasped" (Van Manen, 1990, p. 10). Intuiting refers to an awareness of the experience as well as the processes involved in the experience (Ray, 1985).

The focus is not on the actual facts of the experiences, but rather the individual's description and reflection of the experience. As Colaizzi (1978) stated, the researcher must be present to the participants "in a special way" (p.64). The acknowledgement of the data provided by the participants does not give full credit to individuals. The researcher must be listening with his or her entire being in order to appreciate the richness of the participants' descriptions. Colaizzi (1978) referred to this presence as imaginative listening, being present to the participant in every imaginable way. Eisner (1985) stressed that the perceptions of experiences in isolation does not explore the subtle differences and similarities that are inherent in the unique experiences which extend beyond the classification of specific categories (as cited in Bevis and Watson, 1989).

"Perception involves looking and seeing into experience" (Bevis & Watson, (1989), p. 288). Benner (1984), in her interpretive study of nurses, stated that the expert nurses often began to perceive a situation based upon their intuition or "gut feeling".

The unfolding of meaning is personal and individual and must fit with the person's experience, beliefs, rationale, expectations, and the context in which the situation occurs (Bevis & Watson, 1989). The context in which an event has been experienced is central to understanding the meaning of the situation to the individual. Past experiences, and previous encounters with certain individuals will affect the perceptions of individuals and the meanings that they ascribe to the experiences.

Intuition played an important role in my research as I attempted to try and connect with the participant's reality. I recognized this as I began to make enquiries regarding concerns of the participants.

I had sensed that a Aboriginal caregiver felt that his child was different from the white children who had received transplants and thus perceived that they reacted differently to anti-rejection medication. Thus I was intuitively interested in what explanation or response a caregiver might receive from a physician. I asked a pediatric nephrologist "why do the transplanted aboriginal children have such large faces." The reason given was related to obesity.

I also sensed that the Aboriginal caregivers felt that there was a lack of culturally specific support to meet their needs. I phoned the kidney foundation to seek out what support and information was available for patients and families experiencing RF. I discovered that there was no information that was developed specifically for this aggregate. The dissemination of a standard manual was however permitted, at the discretion of a pediatric nephrologist.

I sensed also, that there was a desire and need for the Aboriginal caregivers to have one on one support and counselling in regards to purchasing and preparing foods that were appropriate for their children. After conferring with the dietitian, I purchased a cookbook which was considered appropriate for renal patients. I also began reviewing my nephrology texts in hopes to find some specific answers, which I could not. As I returned to the participants with my answers, I felt inadequate as the answers seemed sadly lacking in substance. Those experiences illuminated the need for culturally appropriate nursing care that incorporates the values, beliefs, practices and sensitivity to the environment that the individual is from and will potentially return to (Strickland & Fishman, 1994).

### Creativity

Phenomenological methods have been used to study different phenomena in various ways. Hasse (1987) examined courage in adolescents. Jacobson (1994) explored the meaning of stressful life experiences in children. Nursing phenomena was studied by Geissler (1990), and Lynch-Sauer (1985). These studies used different creative methods as well as interviewing to obtain data. Providing participants with the research question prior to the interview was used to generate data (Hasse, 1987). Drawing was used to decrease anxiety in children as well to obtain information (Jacobson, 1994). A pilot study was used to gain research experience and resulted in a question being added to the two initial ones used for the pilot project (Geissler, 1990). One researcher also included diary entries from a book in order to expand a data base

(Lynch-Sauer 1985). From the above examples it was evident that a certain creativeness may be used to add to the phenomenological research enquiry.

I attempted to be creative during my data collection by using various ways of obtaining information. A map of the north was shown to a few of the participants during subsequent interviews in order to help dialogue about where they originally came from. This helped to break the ice so that they could talk about home and family. The discussions that followed this helped reveal some of the themes that I identified which were related to the role of the family, surviving and envisioning the future. Four of the participants gave descriptions about where they were from and how being displaced from their homes gave special meaning to their experiences of caring for a child with renal failure.

During my home visits, three of the participants expressed their creativity by showing me their family pictures and describing their family members. One participant proudly showed me a book written about their elders and shared the inscriptions that her young daughter had written in the book when she was about three or four, which I then recited aloud:

... people, people are friends, they give you their happiness and love  
and that's what counts for the people in ...

The caregiver then described another verse that her daughter had wrote when she was a few years older:

This one is filled with sorrow and happy life. And when she was about  
... I think she wrote this where happiness lives for many years.

Following the interviews, I encouraged children to speak into the microphone in order to hear their own voices if they wished. One participant's child with RF and her sibling tried tape recording their voices and they seemed to derive pleasure from this activity.

### Data Analysis Procedures

The textual accounts of the participants were carefully collected and examined. The experiential data which is gathered allows the researcher to become informed and experienced themselves (Van Manen, 1990). The participants served as co-researchers in their role of validation of the findings. As a beginning researcher, other expert judges such as my research advisor were consulted or conferred with to discuss the findings. As others are allowed to become shaped by this experience, the full significance of its meaning becomes apparent.

I listened to and read the transcripts simultaneously in order to get a general sense of the descriptions. I then began to compile an exhaustive list of theme headings which captured the general essence of the descriptions. I returned to the transcripts and I began to narrow the list of headings into common themes which seemed to fit the descriptions. Prior to returning to the participants, I discussed the themes with my advisor to ensure that there was agreement for the themes chosen. When I returned to re-interview participants, or when I had an initial interview, I would incorporate the themes which were being developed into the interview. I had also typed a list of themes which I gave to participants to review, and which we discussed during our conversation. For example I would state that the theme living in fear seemed to relate

to the time that a participant had first found out that her child had been diagnosed with renal failure and would need to have dialysis or a kidney transplant. Thus I would continue to dialogue with the participants and obtain consensus on the themes which surfaced from their descriptions.

The themes which developed progressed along a continuum and were dependent upon the illness trajectory of the child with RF. Some of the themes were unique to participants and some were weighted as being more important than others. An example was that the themes relating to the details of the RF (ie. Providing complex interventions) seemed less important to most participants whereas themes such as Relocation, and Family support were described as being most important.

### Limitations

One of the limitations that may have affected the validity of the study may have been the hesitancy of some participants, particularly given the traditions of the Aboriginal culture, to divulge their true feelings and interpretations of events that they have experienced. This was minimized by allowing the participants time to express themselves, having repeated contacts, interviewing at their home if they wished, observing participants' verbal and nonverbal behaviour for possible distress symptoms such as nervousness, and using probes to elicit information.

An important discovery that I found was that participants did not like it if I asked them out right if they had "any stories to tell me about their experiences". Following this line of questioning, the interview would come to an abrupt halt with little information being forthcoming. Puzzled as I was about this, I sought advice

from an expert nurse who suggested that the "stories" may have been interpreted as being make belief and therefore untrue. As the participants wanted to describe "real events" and the "stories" were considered to be false, they chose not to dialogue with me about these events.

Another limitation was that the analysis of the data obtained during the interviews was subject to observer bias. Orlando (1961) suggests that the risk of introducing bias into the data is out-weighed by the great depth of information obtained. Further, the goal of the written report was to include as much description as was necessary to ensure the accurate description of the meaning of everyday experience. Transcription of the taped interviews and any field notes were taken promptly, regularly and analyzed frequently (Lofland, 1971).

Some of the reports went beyond the length of conventional unstructured interviews and became life histories, requiring repeated interviewing sessions with the participants (Fontana & Frey, 1994). The use of the validation strategy and discussion with expert judges also reduced the likelihood of observer bias. The participants were given an opportunity to dialogue about the themes that I had identified. My research advisor discussed the context of my interviews and read some of the transcripts from my interviews. Another expert nurse also discussed some of my findings with me and gave suggestions as to how the descriptions could be understood. A significant amount of time was spent in the field during my initial interviews, and during subsequent interviews in order to return to the participants for validation of my themes. I developed trusting relationships with the participants by engaging them in my research

as co-researchers. This is cited as being crucial to ensure validity in qualitative research (LoBiondo-Wood & Haber, 1990).

### Reliability and Validity

There is a lack of consensus concerning the issues of reliability and validity among phenomenologists (Beck, 1994). Tests for rigor in qualitative research are often done according to the criteria described by Lincoln and Guba (1985).

These tests for rigor include:

- (1) Truth value: How can one establish confidence in the truth of the findings of a particular inquiry for the subjects with which, and the context in which, the inquiry was carried out?
- (2) Applicability: How can one determine the extent to which the findings of a particular inquiry have applicability in other contexts or with other subjects?
- (3) Consistency: How can one determine whether the findings of an inquiry could be repeated if the inquiry were replicated with the same subjects in the same context?
- (4) Neutrality: How can one establish the degree to which the findings of an inquiry are determined by the subjects and conditions of the inquiry and not by the biases, motivations, interests, or perspectives of the inquirer? (Lincoln & Guba, 1985, p. 290)

For my study, reliability and validity was addressed using Van Manen (1990) as a guide. For Colaizzi (1978), phenomenology focuses on dialogue. This focus on dialogue means that the researcher must be conversing with his or her participants during some point in the research, on the participants' same level of understanding.

At one point, when I felt I was already well into the interview, a participant asked me "What exactly are you asking....?", "What exactly are you trying to find

out?". In order to respond to this challenge, I replied that I was "trying to put myself in your shoes and see what sort of things have you had to deal with, with having a child with kidney problems". The participant stated "OK". Then I further elaborated "I would never be able to understand it totally because I can't put myself in your shoes". This acknowledgement allowed the interview to flow from this point on.

Member checking was used in this study in order to validate interpretation of data with the participants. The participants were requested to validate descriptions or excerpts of my interpretation of the data collected. This is a method of testing the data and preliminary categories by including the interpretations of the participants from whom the original constructions were collected (Lincoln, 1992). This allowed any discrepancies to be discovered and also allowed for additional information to be added. I distributed a list of themes to participants in order to validate the preliminary findings. There was no disagreement of the themes that were identified, and some of the themes spontaneously surfaced in our conversations. The theme "living in fear" was acknowledged by a mother during a subsequent interview. Also, my advisor read some of the data and descriptions of the data in order to validate the findings.

## CHAPTER FOUR

### Findings: The Lived Experience of Caregivers

This chapter contains the themes, and sub - themes, which emerged during the study. During my initial analysis, all of the themes identified were examined and then collapsed into clusters of themes that were commonly found in the participants' descriptions. Those themes which clustered, or were commonly found, were entitled the main themes. Any other significant findings were then noted and called sub - themes. All of the themes found were included, even those that appeared to be contradictory or did not seem to fit in with any other descriptions. The themes were captured in "phenomenologically sensitive paragraphs", which Van Manen (1990) refers to as "composing linguistic transformations" (p. 95). The themes served as guides for writing. The eleven main themes were: Discovering Renal Failure; Living in Fear; Managing the illness; Relocation; Surviving; Building Strengths; The Role of the Family; Unmet Needs; Envisioning the Future; Enhancing Power and The Meaning of Health and Illness.

#### Discovering Renal Failure

Discovering Renal Failure was an evident theme in almost every description given by the participants. The discovery of a severe and chronic health problem in a child was seen a major event in the lives of the participants. Often there was little forewarning of a health crisis since early renal failure is often insidious and may remain undetected for long periods of time. Under the main theme of discovering RF,

the sub - themes of Initial Discovery and Lack of Understanding were frequently described by the participants.

### Initial Discovery

At times, when there were other health conditions occurring simultaneously, there were fears of other life threatening illnesses and, in the broad scheme of etiologic factors, renal failure was not found initially. Within the context of caring for their children, caregivers described how they had always assumed that their child had different problems since these children had experienced many respiratory infections:

The only thing that they always checked was his lungs cause they were undeveloped and he had a heart murmur and that was the only two major things that they'd tell me. When we bring him to Winnipeg ...

He had a lot of chest infections and I thought that was causing that his lungs were underdeveloped and that's what I thought was the cause. And they'd send him down over here and he'd be on a compressor and they'd send him back to \_\_. We were just back and forth all the time.

... I was taking a course that time. And the doctor phoned me at, at the college and he told me he had to fly him to Winnipeg. He had to right away he told us too what was going to happen. He was going to have a, he needed a transplant as soon as possible because his kidneys were failing

Another participant described how the initial symptom she noted in her child was tiredness:

I didn't find out anything, well I just noticed that he was only tired.

In the next example, a mother described her feelings about the initial discovery being a terrifying experience:

I think she was 12, ... or 13 when I first found out she had kidney problems, like she was getting sick a lot. Like I didn't know what was wrong with her and then, at the same time too, she lost a lot of her hair, eh, her hair was falling out. I thought she had cancer and she's

just scaring me, eh. And she lost a lot of weight and she didn't eat. That's when I first found out she had kidney problems.

In another example a caregiver told of her experience that occurred shortly after she went through a marriage separation. The initial encounter with her child's RF occurred while she was in a Crisis Home, and her child's illness progressed rapidly.

This mother later elaborated on this difficult experience:

They never said anything. Just like one time that when my husband separated, that was the time ... and about four months after that's when she was sick. And we were in the Crisis Home, you know in the Crisis Home and that's where she got sick. Just having a cold first then and week by week. She goes to, she went to the swimming pool so she go sick with a cold and they gave her some cough syrup and then she starts getting sick. That's all I know.

In another example a caregiver revealed that even though there was awareness of a problem, RF was not discovered till further testing was done:

We didn't know that there were kidney problems. Was her high blood pressure. That's why I brought her in and they found out about her, they found out her kidneys weren't functioning right.

In this next example, a stepmother described her first encounter with her child's experience with RF, which had started out as a rash:

... the first time she was sick was last July. The nurse called me, she was starting having a rash, .... she started the rash 14 days and they didn't know what it was. They told me, took about 4 days after, ... the rash couldn't go away and that's when we found out that she had a kidney problem.

Another caregiver described how her child's kidney problems were discovered right after his birth:

They said they had an ultrasound when he was born. That he had one round kidney, wasn't the same size as the other one. They told me that

we would be going to Winnipeg for ultrasound X-ray. They found out when he was born. They made another appointment for him. We've only been here for two times now. And the doctors says that his kidneys are growing normally.

The need to acknowledge and address the initial discovery of having a child with a serious health concern was clearly articulated by one participant:

Yes, first of all we have to face the reality that we have a problem with our child. You got a problem, a health problem ...

In summary, the meaning of caring for a child with RF from the perspective of the urban Aboriginal caregiver is multifaceted and can be likened to a journey along the path of their experiences of every day life. Initially the trip involves the discovery of the illness, where the caregiver finds out that their child is afflicted with renal failure. For many, this was unexpected and a lack of understanding about the situation prevailed.

### Lack of Understanding

For some caregivers, it was not only the health issue that was of concern to the caregivers but also their lack of understanding. This lack of understanding was compounded by having to deal with the stressful event alone. The experience was described by one participant in this next example:

I didn't really understand about it and then I didn't, um, the doctor that told me about it at \_\_, I didn't really understand what he was saying. ... And I didn't like coming here by myself last year cause it's ... anything serious that a doctor would tell me, um, ... cause the Medical Service does not allow, um, two parents to go with the child.

In the next example, a caregiver of a child on conservative therapy revealed that she did not have knowledge regarding the long term plans for her child. This mother did

intend to find out more information from the health care professionals. She described her last visit to the doctor:

They didn't tell me anything. They just gonna check up on her every time and all of us. See how the medications working on her. That's the only side effects she only gets, sore throat. ... She's trying not to take that medicine but I tell her to take it. Said I don't like having a sore throat ...

... We're going down there tomorrow, there's a barbecue and I'll speak to the nurse ... Think she's in on Wednesdays. And then we'll talk to her again ...

In this next example, a caregiver described her lack of knowledge as it unfolded during the initial stages of their child's illness:

Yea. Well, they said something about screening, a lot of screening and they showed us a picture of his kidney and they were, you could barely see them. It was the middle of the night when we arrived here at the Children's. And ever since then we've been here.

In summary, the theme Discovering Renal Failure with the sub - themes of Initial Discovery and Lack of Understanding were articulated by most of the participants during the initial event of their child's illness. Many participants found this experience to be unexpected and thus were not prepared for the news.

### Living in Fear

Participants described many of their experiences of caring for a child with RF within the context of Living in Fear. At times, it appeared as if many of the descriptions of experiences coincided with the initial theme of discovery of RF. However, the "fear" continued even after the diagnosis of RF was established. Three sub - themes were developed from descriptions given by the participants. The sub - themes; Persistence in the Face of Helplessness, Lack of Knowledge and Uncertainty

emerged. Some of the participants lost faith in the words and advice of the health care professionals. Others doubted the findings of the various tests used by the health care professionals. The underlying feeling was one of Helplessness, as the caregivers did not know what to do to improve their situation. Lack of Knowledge prevailed as the caregivers lacked the necessary knowledge to assist them in their experiences of caring for a child with renal failure. Uncertainty was always present since there was so many unknowns as to what would transpire next.

#### Persistence in the Face of Helplessness

In one example, a participant was told that her child was just being lazy, although she knew that this was not the case. She felt helpless, and did not understand what was occurring although she knew that her son was ill:

I went to see the nurse and I told him what was happening and he, checked him out .... then told me that everything is O.K., everything is normal. He's just plain lazy. He just plain a teenager.

This same mother continued to try and seek assistance:

I kept, I kept on taking him to the nursing station. I kept on telling the nurse that there was something wrong with him. He's not, it's not what you said. She didn't believe me until I stopped taking him to the nursing station because I knew every year comes to Winnipeg to, to his clinic for, um, ... his seizure disorder ... And every year they, the doctor do tests on his brain. Do a brain scan. That was [what] I was waiting for on January. He had an appointment and ... all summer I kept going back and forth ... and I stopped taking him to the nursing station in October cause they didn't do anything. They always take him but they just say, there's nothing wrong with him, he's normal. And when I came over here, January, I told his doctor that there's something wrong with him and, I told her about it and told her about the nurse up north. Right away she took the urine and the blood and then she told me to take him back to \_ and not even one week later doctor phoned me and he want us right away back in the city. Cause there is something wrong with \_.

Another participant also persisted in taking her child for care even when she was repeatedly turned away by health care professionals. This participant tells of her experiences which were related to persistence in the face of helplessness:

... well she was feeling sick. We were at\_\_ so I keep on taking her to the hospital and didn't know what was wrong with her. So and she was pretty weak, that's when they took her, they flew her to hospital here. So they took her to another hospital. That's how they found that I guess when they phoned here they had found out she had kidney failure. Came here right away.

... At first she just started out with a cold and she couldn't eat, she couldn't drink, she couldn't pee.  
Took her to the nursing station, the hospital.

... I didn't really know what to, what was happening. At first she just took pills and about 8 months after she went on dialysis for a short time. And after, after that, uh, she was going on dialysis.

Later on, this same caregiver's child was hospitalized. Even though this child was critically ill, the caregiver understood little and therefore felt helplessness about the entire situation:

... she had to stay in maybe for a week and, uh, she was in intensive care. And, I don't know, I don't know the what they did to her that week ... that weekend that she was in intensive care they had to put that tube here ...

... and she slept all the time, you know when they paralyzed her. She slept for the whole weekend. ... Sometimes I can't really understand what they are saying. I can't sort of really understand it, the thing.

One caregiver described her persistence in the face of helplessness due to the repeated tests her other child had to undergo with no answers being found for the child's problems:

... she went for three ultrasounds and they said there's nothing wrong with her and she's taking Tylenol every 4 hours, like to take the pain away from her back. So I don't know what's causing it. So I'm trying to get Dr. \_ to assess her so find out what was wrong with her. Kind of worried about her, she's getting kind of sick too. Maybe I thought, maybe she has the same, the same disease as her.

Cause, um, cause the symptoms he talks about, it's the same things as my daughter is having and I thought maybe she has that too and like they don't know what's wrong with her. And I'm tired of going back and forth and saying, "No, no, we don't know what's wrong."

This caregiver's family felt helpless, thus they also worried about the ill child:

Uh, sometimes they're scared about her, like they're worried about her. Like something might go wrong. Especially when she gets these, uh, symptoms and she can't breathe. And she scares me, like she'll say, "Mom, mom, that's it, there's something wrong, I can't breathe." "I can't do nothing" she keeps on saying that. And if I take her to the nursing station, they don't know what's wrong with her. So there is nothing to do for me at home. That's what I told Dr. \_ so he's going to do more tests on her.

The mother persisted in the face of helplessness and lacked understanding regarding her child's illness. The nurses at the nursing station were not able to provide assistance and they also suggested that her daughter's symptoms may be due to growing pains:

They don't know. They say, they don't know at all. Like these symptoms say she's been having shaky feelings and the tightness, they'll say, they say maybe they're growing pains.

At times the persistence in the face of helplessness turned to descriptions of anger and despair with the health care professionals. This next example was given by the same participant as above:

And sometimes I get mad and get upset when they don't know what's wrong with her and she's really like, like I can tell she, she feels a lot

of pain and she gets, she get her face, her face is changed the colour, like she goes like red and sweaty.

In another example, a father expressed his initial feelings of helplessness and lack of understanding when he refused to accept the fate of his child:

I had an argument with the doctor so many times, I didn't want to face it. I didn't want it. I thought it was they're getting, I didn't think it was true what they were telling me. They told me that he's got a kidney problem which I didn't believe.

The wife of the above participant described how she felt helpless but continued to return to the clinic until finally a decision was made to provide an intervention for their ill son. Soon after a kidney transplant was performed:

... And that's, and from that [time] on we continue bringing him every month to take him back, take him Dr. \_ always check him every month. And then on April, that's when they say we have to do something for \_ . He needs his dialysis. He only had it for 4 months then he had a kidney donor right away.

A mother recalled speaking to the physicians, but not understanding what she was being told. Thus her feelings of helplessness were reinforced as she persisted in trying to understand:

I just talked to her doctors.  
I can't sort of really understand it...

Another caregiver revealed her persistence in the face of helplessness about her child's renal failure. She described how she must learn about anything health related by depending on her spouse:

I read it first and then he'll read it too and then he'll telling me, explaining it. I usually don't understand. ... I have a hard time understanding stuff.

In summary, there was a sense of persistence in the face of helplessness regarding many of the events that had taken place, over which the caregiver had little control. Those included such things as appointments, tests, treatments, procedures, surgery and relocation to a new community. Although there were times of helplessness and lack of understanding expressed by the participants, they often admitted to being given information, but not understanding what they are told by the health care professionals.

#### Lack of Knowledge

The caregivers lived in constant fear of what may happen to their ill child and how their family would be affected. For many, there was a lack of knowledge about the experience of caring for a child with renal failure.

One participant who described himself as a man of few words, and who disliked speaking to many people, expressed how he felt after speaking to his grandchild's physician. There was a sense of a lack of knowledge in his description:

I asked him a lot of time and he would tell me nothing.

When asked if he felt that the doctors were too busy, he denied this. He felt that he was not given information as he was not considered to be important:

No. They don't have to tell me. You don't have to tell me I guess I'm not important ...

This same individual related the lack of information obtained to an experience with surgery that he has had in the past. He also felt that physicians are over paid:

Doctors never tell me nothing too. ... doctors are overpaid.

During one of my interviews, a participant described her lack of knowledge regarding her daughter's polycystic disease as follows:

I think it's there for good, ... He says that the bubbles, they come out, they bubble up in the kidney and that bubble stays in there. It doesn't go away. Unless there's something wrong that they break and then it gets bigger and then the bubble comes in, gets bigger. He said that it's been good like it hasn't changed for the past last year, it's been the same.

Another stepmother shared her lack of knowledge regarding her daughter's nephrotic syndrome and graphically described her experience:

Cause sometimes her blood pressure get way high and her urine sometimes, it's just red, bloody, you know. That's when the doctor send her out. .... she can't walk ...

### Uncertainty

Uncertainty was another sub - theme under the main theme; Living in Fear.

Uncertainty was apparent in descriptions of worsening health. Uncertainty was interwoven within the sub - themes of Persistence in the Face of Helplessness and Lack of Knowledge as it was difficult to exclusively separate the three sub - themes.

In the following example, a caregiver voiced uncertainty about whether other children in the family were being affected by RF:

That's what I'm wondering about cause, um, my daughter, she's having the same symptoms. ... she's been getting sick on and off, having back pains right up to here ...

One participant clearly described the uncertainty that surrounded the diagnosis of RF when her child became ill. The initial incorrect diagnosis of arthritis seemed to make sense to this mother at the time. She observed the symptoms to be related to the

weather and she was quite alarmed to later discover that her son was yet another individual whom she knew who was stricken with RF:

He might [have] arthritis, that's what he said.  
 .... he was having joint pains everywhere in his body.  
 When it was wintertime, when it starts to be cold, he was complaining about his joints everywhere. Like hands can't, can't even move. And that's what Dr. \_ said, he might have arthritis or some other disease, he told me. And then we had to come right back about a week later and that's when he had, ultrasound. That's when they say ... that his kidneys were very small. They were starting to get sick when he grown, those kidneys were too small to work for him and that's why he got tired and didn't want to eat. He was getting too big for those kidneys. And that's how we find out. Another kidney failure.

In this next description, the caregiver spoke about continuing symptoms that her daughter had experienced. This participant spoke in a rush of words, describing the uncertainty related to her fears about reoccurrence of the illness:

Then after her hair grow back and, um, and she's been having, she had these, um, shaking. She'd be shaking like she can't breathe and I don't know what's causing that. I didn't know what was causing that and she had heart po..., problems and on the sides. That's when I knew that she had kidney problems when we came to Winnipeg. She had, she had tests when she, when she first got sick with this, they sent her to Winnipeg right away and I guess that's where they found what was wrong with her. And after that she hadn't been really sick like sick sick. She's been O.K. But since, um, when September last year she's been getting sick again, like, uh, she's getting these shaky feelings. She can't breathe or after, after she has supper, half an hour or maybe 20 minutes, she'll get these same shaky feelings and some kind of chest pain, tightening.

During a subsequent interview, the same caregiver again described uncertainty regarding her daughter's symptoms:

Yea chest pains. It comes any time like is where, when she's sitting down, all of a sudden she'll clamp her chest and say that she's having bad chest pains. Like sometimes she'll want to cry and say it's hurting her but there's nothing for me to do. And sometimes when she's

eating, like right after eating, like 10 minutes, all of a sudden there was a squeezing pain or a stabbing pain she'll say that she's got a chest pain. But there's nothing I can do about it. It lasts like 5 minutes to 10 and then it will go away. But the last 2 months ago, was when she really scared me like when she said she had that chest pain something was ballooning up inside her and she was all red. her face was red like she was out of breath but she got better. I think it lasted her 15, 20 minutes was the worst and I told Dr. \_ right away when he got here and then when he said, he's do a test on it right away. He didn't want to wait to the last minute when she gets sick.

The next description of uncertainty was given by the caregiver of a son who had received a transplant and who also had an uncle on dialysis:

Moving them to the city from back home is like, O.K. here, tie me up and it comes out from your stomach or your heart or your chest ... It's like you're tied up to this place and can't go anywhere. My uncle cried. I heard him cry on the phone. The guy that phoned me yesterday. Called me three weeks ago. He says, I cannot, I won't be able to see my trapline again I won't be able to see my family again, never again ...

In this next example a mother described the uncertainty surrounding the experience of being called about a potential kidney transplant for her daughter while they were in the midst of moving:

They phoned us in the middle of moving, ... They phoned us and, they phoned us to bring her right away. Like they didn't, they admit her in right away. ... I didn't know what was happening until later. I mean she was, she was scared.

During a subsequent interview this caregiver again described her uncertainty and how they were notified about a potential organ being available for her daughter who was on dialysis:

Once that day we moved, on the fourth of January, not on the fourth of January, maybe the second, we were moving and by the time everything got in there, the other house, the phone was, the phone was already working. So we just, everything was in the hallways and

couldn't find the phone. It would be later on about, I don't know, four o'clock. That's when we found a phone and they just hooked it, hooked it up and the phone rang right away. So they said if she wanted to go for a transplant. They asked me first. I said, yea. We'll come over. I just took her for a blood test.

The last description reveals the experiences of two caregivers of a child who was transplanted and was now rejecting the kidney. The mother described her uncertainty and fears about the possible return to dialysis:

But I'm still having hopes. I don't want to say. Like he's going to go back. I'm still waiting for it to get better. It might. I'll believe it when he, I see him on dialysis again. I don't want to see it.

The father then described how his son was reluctant to visit the dialysis unit:

And he doesn't like to go down there, eh.

The mother continued to describe the following:

One time he told me if ever my kidneys failed, I don't want to go back on dialysis. But he hasn't said anything about it. ... and he doesn't want to go back on dialysis.

In summary, a number of examples have been given to demonstrate the second main theme living in fear, and the sub - themes persistence in the face of helplessness, lack of knowledge and uncertainty. Most of these descriptions revolved around the lack of knowledge and understanding about RF and what the role of the caregiver could be. Despite their persistence, any options for gaining information did not seem to be presented to the caregivers at this stage in their experiences. This left the caregivers in a state of helplessness after they first discovered that their child had RF.

The constancy and permanence of caring for a child who is experiencing RF, was found by most caregivers to include uncertainty. Vivid descriptions of the

experiences which demonstrated this uncertainty were given during many of my interviews with participants.

### Managing the Illness

Many different scenarios were described by the participants as they recalled and shared their everyday experiences of managing care for their child with RF. Two sub - themes, Vigilance and Doing The Best That I Can, were evolved from experiences of parents who had children on conservative therapy. For the caregivers with children who were transplanted, another sub - theme entitled Providing Interventions became evident in addition to Vigilance and Doing The Best That I Can.

#### Vigilance

Many of the caregivers gave descriptions of the vigilance necessary for the ongoing care and protection that they felt their child needed. A mother with a young child on conservative treatment discussed her experience:

I just watch him, watch him carefully. And the doctors here told me last year, they told me not to worry about it cause they had lots of kids like that.

The next example was given by a mother with a child on conservative therapy for RF.

She described her attention to her child's symptoms:

When I, when she's starting like getting sick, when she doesn't feel good, that's when I worry cause it could be the kidney, I think, eh. And I start worrying and I'll take her to the nursing station. Like I'd watch her and watch the kind of symptoms she has so, uh, so the doctor will know if there is something wrong with her.

In the next scenario, a grandfather caregiver described what he observed during the course of his grandchild's illness, and then later after the transplant surgery:

... that time he was, it went down you know. He didn't eat or sleep. Hard to sleep ... After the operation, after a couple of months, maybe, two, three months, he's O.K.

The next caregiver did not perceive a difference in the meaning of caring for her child after transplant surgery. The vigilance continued to be necessary. Although she was relieved to have had the peritoneal catheter removed, and she felt grateful for the transplant, she still wished that things were back to the way they once were:

I don't know. I just feel the same way cause, you know it's not, it's still the same and, it's almost the same thing but the only difference is he's, he doesn't have a catheter on, sticking out from his belly, you know. He still has to watch over things like eating and the way he moves, you know. Can't do, he can't do the things he was doing before when he was normal.

Like, um, when he's eating, normal, eh, ... I still have to keep an eye on him what he's eating, you know, after the transplant but in a way we .... you know, good about having his transplant. Not having that thing here.

In a subsequent interview this same caregiver described her vigilance;

Right now, like myself, I'm really concerned about his height. Yea. And when you say the donor and after that he has lots of pills and then he have to, he really has to work for it, not to take it, the pills, and all those pills, what it's called, and it's very confusing. But after a while you get used to it.

This same mother also described how she noticed her child's diet changed after the transplant:

It's changing but like when he was in dialysis he can't eat banana and tomato. But right now he can have tomatoes and banana but just only a little bit.

But, I mean, every day when he wants to eat, he wants, he doesn't want the same food all the time. ... He wants something different the next day but I don't know what, what am I going to give him? Cause I only have the things I gave him before.

In the next example, a mother described her vigilance of her oldest child during the time of her transplant surgery. She described how she had to leave her two other young children in the care of a housekeeper in order to be with her daughter, to keep vigilance over her during the transplant surgery.

Got me a housekeeper which was 8 till 4 or something. And, ... so I came down here about 8 to 4 and then went back home. I just went back home for supper and then I would come back here.

In the next description, this same mother found it difficult to allow her child to have certain privileges such as a sleep over at a friends house, due to her Vigilance regarding maintenance of the schedule for the transplant medication. She described how she cared for her child by ensuring that her medication was taken as prescribed:

Before she, if she doesn't, if she forgets again, next time they won't sleep over any more. She tries to take them. She knows that I'm not there then. A couple of times last week she forgot them. She's getting better now taking her pills by herself.

In the next description, caregivers revealed how they dropped everything to maintain their vigilance and to be with their ill child. A wife spoke about this event first:

We left all our furniture there, right.

She then emphasized the meaning of this by saying:

Everything

Her husband agreed and then stated:

I never went back there, eh.

These same caregivers then described how they left their other children at home in their community in order to maintain the vigilance of their ill child:

Somebody took them to \_\_\_. I just left them in \_\_\_. With a sitter. And there was somebody from \_\_\_ that took them back to \_\_\_. She flew from \_\_\_ to \_\_\_ to pick them up and then she flew back to \_\_\_. It wasn't until Christmas that I saw them again. ... Probably about 2 months.

The husband reaffirmed this vigilance by stating the length of time that they remained away from their community:

Two months. Cause we came down here when, sometime in October, eh.

A father of a son who received a transplant, provided a revealing description about the vigilance and care that he gave his son, affirming that he did treat his son differently:

Even if he, if he didn't have kidney dialysis, you know, kidney failure, I would still treat him special. I treat him more special when I found out he had kidney failure. And I have no doubt about it I treat him in a different way. I think we're over protecting him, we have to keep an eye on him all the time.

In summary, all of the caregivers described varying ways in which they cared for their child with RF within the sub - theme of vigilance and described the meaning of these experiences for them. For some of the participants, vigilance involved close observation of their child with renal failure and the lack of privileges such as a sleep over. Attention to the diet and/or medication was also described as part of the vigilance. For others, maintaining vigilance meant being away from their other children for months, or leaving them in the care of a housekeeper.

### Doing the Best I Can

For some of the participants, it was evident that life was busy and although there were some supports lacking, they just tried their hardest to do the best that they

could with what was available. This is the focus of this next sub - theme; Doing the best that I can.

In the first example, a mother caring for a child receiving conservative treatment of RF and looking after her five other children, described how she managed:

I just try and take care of my kids as good as possible. ... I can't, can't even take care of her, then the best way I can.

In the next example, a young single mother described her beginning experiences with providing her child with dialysis. She experienced fear of the procedure, and felt tired at times, but managed to successfully perform the treatment for her daughter at home:

Well, it's O.K. It tires me sometimes. I was scared of it at first but it wasn't too long that I was scared of it.

The participant then described her daughter's involvement in the dialysis treatments.

She also described her experiences with tube feeding:

I think she was interested but you know that there's a lot of work to be done, to do there. It was tough to do.

When she had tube feeding when she couldn't eat too. So she, they put a tube feeding in. ... Ah, it was ... it out. Every night she couldn't, sometimes couldn't sleep and she was having. Last 3 months when she was on dialysis. ... So you don't even eat. You just drink a little bit. She didn't eat.

The next example is a description given by a mother with a child on conservative therapy who detailed a busy life of caring for a total of six children, four of her own and two foster children. She described how she had family support in caring for her ill child:

Sometimes I don't know what to think .... my husband and my father and mother and the nursing station can, uh, come out to help me. And especially my mom's here ... cause I have to work ... and I have a family I come to take care of too. It's hard. Looking after the families. .... Monday to Friday. Sometimes I work weekends ... I have to support my family too, you know. My husband's working too but still need.

To summarize, the descriptions the caregivers gave about the meaning of caring for their child with renal failure varied, however, the underlining feeling for the descriptions given revealed that they were doing the best that they possibly could.

### Providing Complex Interventions

The sub - theme, Providing Complex Interventions, emerged from data provided by the caregivers of transplanted children. Some of the caregivers found that providing difficult treatments to their child was hard work, but they endeavoured to learn the necessary skills so that they would be able to take their children home, or at least become more independent and able to perform self - care.

In the first example, a caregiver gave a description that demonstrated a sense of pride over her family's accomplishment in learning a new and difficult skill. There was almost a sense of disappointment when the child was transplanted. This disappointment was because, although they no longer needed to perform the dialysis treatments, they still had to stay in the city for follow up care by the health care professionals, whereas they could have returned home on dialysis:

We did that for two weeks at St. Boniface. He knows how to do it too and we were starting to, very, uh, familiar at it and I think the dialysis, .... and then he had a donor. And right now he's ... keep changing, that's why he don't go home yet cause they have to keep him, Doctors have to keep an eye on those pills.

The caregiver that shared the next description revealed the complexities of the care required to allow her to bring her child home after a lengthy hospital stay. She also described how important this was for the family:

After a while he recovered real fast and the nurses told me that I wouldn't be able to take him home until I knew how to do his blood pressure and I had to do all those things. Tube feeding him. And I wanted to do it. It was something I wanted to do cause I wanted to take him home and I had to learn. I remember that first time I took him home I couldn't believe I was taking, actually taking him home. I didn't want to use a taxi. I didn't want to use a car. I was pulling him on a wheelchair. I took him home on a wheelchair. You know he was so happy.

This mother then described what it was like caring for her son at home:

We had to put a bed in the living room cause we had to watch him all the time. He was on tube feeds and he, he'd throw up, eh, that tube would come out and he'd choke on it sometimes.

I got used to it. They didn't really bother me cause it was the only way he could get better. If I didn't do it, he wouldn't have been like this, like I wanted to, I didn't want him to stay in the hospital. I wanted to be with him and I wanted him to be with ... his brother and sister. There was friends that came in. He was happy and he wanted to go back to school and I think that's what made him better.

In summary, the events that occurred during the individual illness trajectories of the caregivers' children were very different and unique. The importance of preserving the health of the child at all costs was of paramount importance as the caregivers strived to perform self-care to the best of their abilities. The caregivers managed the illness by maintaining constant vigilance and by providing complex interventions in the spirit of doing the best that they can.

## Relocation

Relocation was a main theme that many of my participants described. They attributed relocation as being the major cause of some of the difficulties that they experienced as they had to move to the city in order to obtain the necessary health care services for their child with renal failure. The losses that the families experienced due to travel and relocation became apparent during my interviews. The participants shared how these experiences gave special meaning to caring for a child with renal failure.

Adaptation to a new community was experienced by all of the participants who had children that required a kidney transplant. Some participants related problems that extended beyond the RF:

Never mind about the dialysis itself, just the change of living, living in another place, it's scary. And on top of that you have to face the health problems of your child and you can't really think straight sometimes ...  
. All throughout the time I'm scared.

Two participants described events that they experienced in their younger years and how these events related to their experience of caring for a child with RF. The first example was given by the mother of a transplanted child. She described how she was a young girl living in the city in order to attend school and here she experienced what her husband described as "culture shock":

... well we were, when we were in school, there were all nuns, sisters. Didn't have anybody else until when we came over here. I was over here. And I went through the same thing that he went through I had never seen anything in the city.

I was very scared. I [was] even scared to talk to somebody, even the teacher. ... my teacher, I can't even talk to you. I don't even know

about counselling, counsellor, school, where I went to school. Go see your counsellor, tell her about anything you like to know. I couldn't even do it, couldn't even talk to her. I was scared. Nobody would tell me what, what, uh, over there at \_ we have principal and the teachers and I we didn't have counsellors in school. Over here they have counsellors in, a, I can't even talk to them.

Her husband then described some more specific details about his experiences:

... even to get on a bus, talk to the driver, get scared to talk to him. You're closed up, you got a shell. And you can't go anywhere, you can't do anything. You just got to break it.

The mother continued to describe her experience of being lost in the city:

I was like totally lost at the school. ... I was trying to go home over there but I didn't know where to go. And I didn't know what bus to take. So it's for me, how can the bus work? ... one of them said could you give me a ticket. I said, what's this? I don't even know, she didn't tell you, she didn't tell me how I should go about it. But one of the things she told me, don't lose this. That's it. (chuckle) And I wouldn't want to lose it until, until I wanted to go home and I saw those students, they had the same tickets that I have, my classmates I watched her and they threw it in the chute that ... and so I threw it in there. I didn't even know where to go and I got lost. ... I didn't even know what to do. So somebody came over and kind of helped me. There was a girl, a native girl and I talked to her. I talked to her in English and then I told her, I'm lost, I don't know where I'm trying to go. But when I told her where I'm trying to go, she didn't know where that thing is. ... she told me I had to tell the bus driver. So I had to go with her ... and she gave me the ticket I think and they told me where to go. That's how when I, that's how I got home. There's almost, already nighttime when I got home.

For one young couple who had to leave their community, many fearful events took place. Besides having to leave their two other children and all of their belongings behind, they slept in an armchair for two months in the hospital:

We didn't have a place to stay so we both slept at the, you know those armchairs at the children's?

The spouse of this participant continued to explain the experience to me:

We had an armchair like this. This is where we used to sleep. Me and her used to sleep there, both of us.

Adding some humour to the situation, the wife then followed with the following statement:

We were small at that time so we fit in. (laughter)  
We slept there for I don't know how long. Probably 2 months. ... We didn't have a place to stay.

Although the event occurred some time ago and not all of the details were clear, the lack of services, related to survival, was mentioned:

Well, well Medical Services couldn't pay for, um, I don't know what happened there. I don't remember but they couldn't give us any support because, uh, we weren't living in the reserve at that time. And for meals, we ran out of money too. And, um, the only time we'd get something if his father sent us something and we had to budget that money.

The caregiver above described how they now received little money to care for their ill child:

Still a little. Not enough but I guess ... this is how much they can give us just a little, no more than that so I'm having a hard time.

The next description was given by one parent as she recalled her initial experience of having to relocate to the city with their ill child:

I think if you live in the city here that's nothing to look forward to being in the city. There's nothing. It's not like living up north. You have all the freedom. Can go outside. You can breathe clean air. You can go down to the bank. You can do whatever you want, it's free. But over here it's not like that. You step out, you look outside, there's nothing to look at, just a wall again ...

.... there's so much noise. So much disturbance.

I remember that first time I was here. I had a hard time with the air.  
.... I felt sick all the time. I couldn't stand the fumes from the cars.

That was the one thing that bothered me a lot. But I got used to it. Was nothing to do. Go eat, eat.

In the next example, survival among aversive living conditions became evident. A mother who cared for a daughter who had received a transplant attributed her daughter's poor health to their present living situation. At the time of the interview, this caregiver and two of her three children managed to survive as they lived in a two bedroom house with eight other persons, one being a newborn. She hoped to find a better place to live:

I guess there's a lot of people that are sick over there, like colds and she can't take it so gets a cold easily. Like she says she has a cold all the time. So we're just thinking of moving back some place ... not right here in Winnipeg.

The caregivers would often describe unmet needs related to travel and relocation to the urban environment. The experience was often a positive one if it was short lived and if a partner was able to accompany the caregiver. Those who had to travel alone with an ill child perceived this as being a negative experience. One of the caregivers that had to fly in to the city in emergency situations described this as being the worst problem that she had encountered in caring for her child with RF:

The only problem I don't like is, I don't like flying here and my husband too ... I get very tired sometimes.

In the next description a caregiver revealed experiences related to his youth, and the unmet needs he had experienced during his quest to receive formal education. The losses that resulted came from relocating and were related to caring for his child with renal failure were also described:

... there's one more thing that I want to say. Uh, the way we live back home, we do have some, uh, a lot of the young people like us, and I still consider myself young, with the lack of education that we have, we still had some funds when we went to school ... My education wasn't good and I only went to schools as far as Grade 10 and my parents wanted me to stay home and work. They wanted me to quit school. I didn't want to. I've been always good and I've been always, have a good grade. And I, my grades would usually be around B's and A's. I went to school at St. Boniface. I, uh, learned typing, French and uh, my first year was the hardest cause ... by moving. I had never seen a bus so far, I'd never seen a phone. I was 16 when I came to the city. And a lot of things were just my first time and it was really scary and to go to school with all the whites and that just by being in class, you don't feel you belong there.

And I wanted to stay in school. I went home for summer and my dad said, O.K. that's enough. You're gonna stay home. I really wanted to come back, never did, never had a chance. So, uh, when I kept going out, coming back to school, I wanted to do something. I just can't stay home ... So I went to the priest again looking for a job. I went to the nursing station for a job. I went to the only store we had in \_\_\_ looking for a job and I had a lucky break. They offered me a job. ... And I end up there for 10 years. And I always admitted that I wanted to go back to school. ... I want to mention this to, uh, to you. And we do have work over there. Some of us are fortunate enough, lucky to work and we're 2 people who were working when I was told that she had a kidney, she was working and we both had to let our jobs go. Move into the city and now they're telling us to be on, to go on welfare and that's another big change that we have to adjust to now. We realize that we, we went by, just by coming to the city, we were lucky that we had savings. Especially with the, like the first summer that we were here that's what we were living on, our savings. And we, of course, we applied for UI and now, since a year now, we've been on welfare. The interest in looking for a job is not there, they've given, I did ask, we did ask for, a while to go and teach. She was a school teacher ... We had a pretty good job.

We could do more than make it, but still just by relocating there's a big change.

A caregiver that had experienced negative times in the city as a young child related what had happened and how these affected her perceptions of caring for her child with renal failure:

It was harder then because I didn't come with an escort. ... I was about 10 years old, 12 years old. ... And my mom and dad would just go put me on a plane and somebody was in, that person was looking after me and somebody picked me up here at the airport to take me to the hospital and they'd leave me there. And I'd get so homesick.

A participant who had relocated to the city described their needs in relation to how they had to travel to and from their community in order to visit friends and family :

... but in summer time we don't have any road. Go by boat. We don't have a road here. ... Only by air. ... But they travel in winter time, they travel back and forth by road using the boats and travel the waters in the summer time. Most of the time we can see our relatives in winter time ... unless if we go fly in there for a few weeks. (chuckle) Too expensive to fly out there. Can't go. Very seldom we do by air.

In the next example a caregiver described the needs that were germane to being relocated from a different community due to caring for a child with RF:

Registering the kids in school is one of the biggest problems. Any parent, good school, like us, we don't know how to register kids, we don't know how to teach our kids how to get on the bus, get in the car, how to use the phone, things like that. While, back home, we take everything for granted what's around us. And we're told to change, ... makes us scared.

In summary, the caregivers described how difficult the experience of travel and relocation could be while caring for a child with renal failure. The everyday tasks that needed to be accomplished seemed insurmountable at times when caregivers experienced being uprooted from their familiar surroundings, family and support networks. The children and the caregivers experienced unique unmet needs which

signified the many losses that they have had to endure with in the scope of this illness. The quest to survive was evident in the persistence of the caregivers as they strived to adapt to the relocation experience. This gave special meaning to their day to day experiences as they cared for their child with renal failure.

### Surviving

The next main theme is descriptive of the basic instinct of survival. Even throughout the dire circumstances of caring for a child with RF and all the complexities that accompanied this task, the caregivers gave descriptions of how they personally managed survival. Within the main theme of surviving, the three subthemes Providing Nutritional Needs, Preventing Harm and Persisting in the Face of Barriers emerged.

#### Providing Nutrition

Many of the participants described the special dietary needs of their children. For some of the caregivers providing nutrition was the most difficult aspect of managing the RF. Their concerns were justified, since the diets prescribed were unlike anything the families were used to. For other participants, their children did not care for traditional foods, or they would eat both the traditional and the non - traditional foods. Caregiver's beliefs about the value of nutrition became evident in descriptions of their families's dietary concerns. The following examples were given by the mother of a teenaged daughter presently receiving conservative treatment:

She eats herself and just takes everything, she, she wants, whatever I cook. Like she'll eat lot and I don't know where it goes. Try, try and get them to eat wild meat but they won't. They mostly eat pasta and I guess pork chops, hamburger, beef and all that.

I always boil water, boil water and cool it off and they make juice and milk. Coffee. She drinks coffee a little bit and sometimes tea and canned drinks. But I don't let them drink that much cause they're not good to drink a lot.

Another caregiver with a child on conservative treatment described her daughter's nutritional needs and then elaborated on her concerns for her only daughter:

And they're going to put her on a special diet now cause she was 50 pounds overweight for her age. And she was growing too fat. ... So she has to talk to a dietitian now.

... I try telling her, you know, to cut down on everything. She doesn't agree. She likes fatty foods she eats a lot of junk. So I get mad I get angry. So I listened to that dietitian, so she talked to her once and I'll ask to talk to her again.

She would listen. I want to see her grow up and she's too young to have kidney problems especially when she's the only girl for me. I'm not able to have any more kids.

In the next example, a grandfather caregiver denied having to prepare a special diet for his transplanted grandson. He described his grandson's dietary habits by naming the different foods that he commonly ate:

By just eating the plain thing, baloney, that's all he'll eat sometimes. A lot of time he eats bannock. Bananas.... always eating banana ...

For one mother of a transplanted son, her son's dietary needs were found to be a major problem which she attempted to solve in different ways. Not only did she try to get assistance from her own family, her community, and the health care professionals, she also questioned how other caregivers of children with RF managed:

What I've having a hard time is ... a food to get. I don't know how to cook them. I try to ask the dietitian to tell me what to have from the store. But we're having problems cause we don't have enough to buy those things, those kind of foods because they're very expensive that I tried to get it really, I tried to cook, like I don't use any salt when I

cook for him. I only boil everything but you can't have any canned foods either cause that's too salty.

... It's, I'm having a hard time myself. When I go to the store, I really, I really can't think of something that would cook for him and I need some advice or somebody to tell me what to have. Like they still ... only give me like lettuce, vegetables, some vegetables you cant' give to him. Like tomato is too much potassium ...

... I try to ask some food [suggestions] from our ... my mom, I asked her if she could send me the native food and they don't always have it any more cause there's hardly anybody going out any more, like going to the bush or trap line or go fishing. There's hardly anyone doing that any more back home.

And he really like the wild meat but we don't put any salt on anything. Just cook it and it's really good for our diet first but we can't have it all the time cause it's hard to get it.

The next example demonstrates this same mother's attempts to solve her dilemma as she described meeting with the renal dietitian and her son's physician. The mother went on to describe concerns and questions about others caring for children with RF and also offered suggestions for some solutions:

Two times already I talk to her and these are the only things she gave to me like vegetables, don't put any salt on it and she mentioned about the meat, like over here meat is different from ours. Over here meat is too fattening. Even if you just boil it, there's a lot of fat in it and you really have to work on it when you want to cook it. Or when a person is like that of kidney failure, you can't just give it to him like that. But that's, well like me and him we don't have any strict diet. We just cook it and eat it. No problem. But those things, that's the problem I have getting food for him and the doctor told me those things are very expensive and I always told him to write a letter so I can take it to Assistance Welfare so they can see how much it cost and because they give us so little that we can't buy anything. You know we have to buy food for the whole month.

That's the other thing. We have, well like myself, I'm very concerned about the others. What are they doing with their food when they have,

uh, after kidney donor? After. How much do they have for the food. Do they have a hard time too? I'm wondering.

What are they doing? What kind of food are they having? Are they having a hard time to take food like that, you know. We should have a dietician only for that too. Give out information what kind of food they should have, you know. They can give out the recipe ... What they can give, what they can cook, ...

In the next caregiver's descriptions, finding a source for traditional foods was not a concern, however limiting the child's diet while living in the city was a concern:

That's what he wanted to eat all the time is wild foods, like fresh, you know, fresh.

Even though When I was living over here, eh. We, we get those things. My dad sent me those things. My cousin sent me those things.

But there was a problem when he goes out he wants to eat and eat and he, and he even after he just ate at our house when he goes out again he wants to eat. He's just eating anything.

So that's the problem we had over here. But over there it's not that. It's no problem cause there's no restaurants there.

The caregiver then went on to describe the importance of the traditional ways of preparing food:

We cook things in an open fire. It's not like burning stone and you add, you add something to the stone and it tastes bad. ... That's bad. We use wood over there. It's not, you don't add fuel or anything, it's just fire. And it tastes good. The food tastes good when you cook. And that's the main thing that I like over there. You can go outside, make a fire and just cook.

### Preventing Harm

The caregivers described different ways of keeping their children safe and protected from any harm. At times it was the avoidance of potential physical harm, while other times it was the prevention of psychological and/or spiritual harm that

was foremost in the caregivers descriptions. In the first example, a mother expressed concerns about her transplanted daughter's physical safety:

Sometimes they play, the brother and sister. I tell her brother not to play so rough with her so sometimes kicks her. This upset me.

He kicks in her stomach. And she was, she kind of protects herself too.

In the next example, the same mother described how she protected her child from the fear of knowing about a potential transplant until very soon before the actual surgery:

But I didn't tell her anything. I just took her for a blood test. Uh, well she knew a little bit but I didn't really tell her. She kind of knew what was going on but later I told her she was going to get a transplant.

She also described concerns for her child's psychological needs after parental separation:

... well we, at first they were trying to talk to her, that councillor. That's before we knew that, uh, she was sick. We were trying to work on her cause she was feeling pretty bad too.

Caregivers would often describe ways in which they would try and alleviate the discomfort from the physical symptoms that their ill children were experiencing.

In the next description, a mother describes what she does for her adolescent child's discomfort:

Just trying to calm her down when she gets like that to lay down and after a while she gets better. I'll try and make her rest, not to move around a lot.

In the next description, a caregiver talks about protecting his son from the recent news of his beloved grandfathers death. When his other grandfather had died, the child had required professional help to deal with that event:

He see the psychiatrist here too. And then he, after, going on, came to see a psychiatrist again but, but his grandfather died last, two years ago sometime, eh. My mom's dad that's. He was lonesome cause ... he loved his grandfather very much, ...

The father disclosed that the son was not yet aware of his grandfather's demise and felt that it was too soon to give his son the news:

Cause it's too early. It's only two months. ... It's too early for him to know that. He doesn't say anything right now.

This same caregiver identified other significant family members and friends in his life who his child could relate well to as a means of preventing harm:

He's got friends. He's got his uncles. One, one that he talks to mostly ...

To summarize, many of the participants described experiences that fell within the context of preventing harm. The importance of following their own cultural beliefs and practices became apparent within this sub - theme of Preventing Harm.

#### Persistence in the Face of Barriers

The last sub - theme, of the main theme Surviving, was Persistence in the Face of Barriers. As caregivers strived to provide optimal care to their child with RF, Persistence in the Face of Barriers was an important aspect. In the first example, a caregiver described how her ill son persisted in going to school, despite the fact that he was not feeling well:

But he always goes to school every day, never misses school.

.... when he's out of school he gets very tired and just goes to sleep ... he won't eat or. And on weekends he just sleeps and tired ...

The next example is a description of one caregiver's persistence, despite a lack of support from the nursing station that attended to this ill child with RF:

I kept, I kept on taking him to the nursing station. I kept on telling the nurses that there was something wrong with him. He's not, it's not what you said. She didn't believe me until I stopped taking him to the nursing station because I knew every year comes to Winnipeg to, to his clinic for, um this is where the seizure disorder too. And every year they, the doctor do tests on his brain. Do a brain scan. That was I was waiting for. On January.

He had an appointment and I have to. That was on, I stopped taking him to the nursing station in October. And all summer I kept going back and forth and then when they start to, like, on taking him to the nursing station cause they didn't do anything. They always take him but they just say, there's nothing wrong with him, he's normal.

The next example is a description of how this same caregiver persisted against medical authority and advise to leave her ill child in the city while she returned home to her community:

When he was about, I don't know about, I don't know how old, almost 2 years old that time I noticed he was sick like with... and fever and I brought him here and that's one thing, that's the only thing is I get told or we did, me and my husband, doctor told me to sign a paper so I, so my ... I can't, he can't stay there I think you have to take care ... He might not, you can't take care of him, he says. Like you can't always fly up north back and forth with him. And they tell me to stay here with him. But I didn't want to stay here, I want to go home. And that's when they ask me to write a form to saying for him to have a foster parent ... so I said no. I always said no.

This mother described how she persisted in attempting to get native food for her child. She also persisted in seeking assistance from the dietitian and had spoke to other caregivers:

And it's very hard. It's, I ask around even my sister still cooks with a little bit moose and meat and gather like berries. ... What they can give, what they can cook, you know what I mean? Kind of a, that kind

of a diet someone should have especial specially for those kidney failures. ... Cause the only thing they just say just give them, give him this and this and that. Like he can have lettuce, he can have lettuce, that's very light food. You give him that everyday but he gets tomatoes and he's gets tired of that. He must have some other food. That's, I was just wondering. I've been having a hard time about the food.

I'm going to have, I'm going to have to phone. The dietitian phoned me last week and I told her what I told you. My son was having his surgery she wanted to talk to me and him. She told me when you're ready, phone her and make an appointment. And I'm going to do that.

I don't know but there's only one, one, my cousin, her son had a kidney transplant and I spoke to her but, um, I guess she's having the same problem. Having a hard time finding what she's going to give to him. And my son is not too, my son is not that fussy for food. But hers, it's different. He sees that ways kind of, he wants what he had before and it is difficult for her. My boy is not like that. But sometimes he wants another, different food than the one I'm making.

In the next example, two caregivers described an incident that occurred during a medical crisis their child had experienced. Both the mother and father recalled their child's persistence in his desire to stay at home. Later, they described how they assisted him even though he was extremely ill and had little strength when he finally chose to seek help. The father described the initial events:

That first time he got sick, he got sick. He didn't want to come to the hospital. He didn't want to. And then maybe a couple of days, he says, take me to the hospital, I'm sick.  
After 3 days, eh.

The caregiver mother added some details to the description:

Carrying a bottle around and he was spitting blood. He kept spitting on that bottle. He was just walking around with that jar.

Next, the father continued:

I said, O.K. He just told me to phone doctor \_\_\_ and tell him I'm sick. But we just came back to the Emergency. He didn't want to take a car,

eh. He only wanted to walk. He wanted to walk here, eh. So I, so I brought him. He walked over here. The only time I carried him was across the street from, uh, William ... just across here.

The mother then described in more detail:

Yea. He'd stop for a while cause he was in pain and then we'd stand there with him on the sidewalk till the pain goes away.

The father continued:

And then after that, the ... I went to Emergency, he was still walking and then on the examining table

The mother interrupted:

He climbed up.

The father affirmed this and went on to graphically describe the next critical incident when their child was taken to the resuscitation room:

he climbed up and then said, I want to go to the washroom. He said he wanted to go to the washroom, eh. So he walked down from the table, on the examining table he walked to the washroom.

... He went inside all by himself, he got out, he walked to the room again and I was, I don't know what I was doing that time. Anyways I was following him, eh.

... I was behind him, eh. And then when I, when I was going to the room, I met him already. ... there was blood on the bed, wasn't even moving. Wasn't even moving and they were rushing to the, what do you call that room, the rece...

The mother described the following:

Yea, so he climbed up in and he told me not to leave him. So he got hold of my hand and he was holding my hand saying, don't leave me mom, he says. And I was looking at the blood pressure and every time it went on it got lower and lower.

She continued on, recalling every detail:

And I called the nurse that they should come, that she should come down. She checked the blood pressure machine and it was down already. And he was still talking to me. And, um, they told me to get out of the room but I couldn't because he was holding on so tight and then I could see that he wasn't starting to talk, just say, mom, and he didn't finish his words, eh. And they just pushed that thing out of the room. They were in a hurry because his blood pressure was really down. They threw me out on the reception hall. I was sti ... , I was still hanging on to the bed. They told me that I had to leave. It was about 2 hours before they came back. And they told us what to expect then we see him in, when we go back in.

The father of this ill child described how his son had felt as he lived through his near death experience:

When \_ was, when he felt better, eh, he wanted to look for that room. He knew he was there in that reception room, eh. He knew that. ... What he said was, I couldn't move, he says ... and I couldn't see anything. Couldn't see anything and he said he couldn't move. But I always heard my mom crying, he says, when I couldn't move, I couldn't see anything. I only saw a big light in front of me.

In summary, the caregivers described many different experiences of Persistence in the face of barriers and divulged the meanings of these experiences within the context of the main theme of surviving.

### Building Strengths

It was within the context of Building Strengths that the caregivers described their perceptions of the experiences of how they have learned to care for their children with RF. The sub - themes within the main theme of Building Strengths included; Learning About Health Care, Learning To Trust The Health Care Providers and Learning Self - Care.

### Learning About Health Care

Most of the caregivers described various ways of how they cared for their children by learning about health care. Health care professionals were the key informants for these caregivers, although it took time for the information to be understood. This first example is that of a mother of a child on conservative therapy. She described having home visits by a nurse. She felt that the nurse giving her daughter information about her weight problem would also be the key person to help them learn about the child's particular health needs:

If a nurse would talk to her once in a while about her weight problem, she would look and listen around the heart. To pop in on her.  
We have a nurse coming by the house every 3 months I think, and check her blood pressure, it's the school nurse.

In the next example, another mother described how she cared for her daughter with regards to learning about the relationship between blood pressure and kidney function.

She began her description with talking about the X-rays her child had:

I seen them in the 92 I think I seen them, the last time I seen. It looked the same. In 94, Dr. \_\_, he had said they're still the same, nothing changed with that's good he said. Like she hadn't any high blood pressure or anything.

And if you notice that if she start having high blood pressure that means there's something wrong with her kidneys, something is, I guess, changing. Oh, I've been watching her. She hasn't had any high blood pressure, just have pains in her chest.

Another example of learning about health care was given by the mother of a child who had received a transplant:

At first, it was hard for us, they told us ... things she couldn't eat but before she was had done dialysis, but now they tell us she can eat anything but not to put that table salt on.

In the next description, a father talked about what he had learned about the cause of his child's kidney disease:

They have never told us what caused it ... The only thing the doctor told us was you could have the inner family members ... But I don't, I don't have anybody in my family that has a heart or kidney problem. I don't know if I told you,...so I told him most of our relatives doesn't have diabetic sort of health problems.

In summary, caregivers were able to articulate the knowledge that they have gained in order to care for their child with renal failure. Some of the details and the various facts that were discussed were complex and hard for the caregivers to understand, however, they did have faith in the knowledge of the health care providers.

#### Trusting the Health Care Providers

Trust is one aspect of care that is crucial to the caring relationship among the health care providers and the caregivers of a child with RF. One caregiver described how it was crucial for Aboriginal people to allow the white people to enter into their Aboriginal communities, to work with them and to learn from each other:

... they were planning to have all natives, teachers. They wanted all native staff. Aboriginal staff. And I'm totally against it there. I think everyone of us has something to share that everybody could help to share. How would a child who's had um, who was brought up from nursery to grade 12 to be seeing only native people all the time. How do you expect them to get, to adjust, to get to know the white people? And, uh, you gotta get, you gotta mingle, you gotta share in a, by sharing you get a better world to learn.

In the next description, a caregiver found that she could trust the health care professionals to care for her ill child and now wanted to have help for another child that she had concerns about. She felt that she would like to override the nursing

station for advise and go directly to the nephrologist in the city whom she would trust:

The other one is starting to scare me, like I'm getting, I'm starting to worry about her. That's why I try to see Dr. \_ before I leave. I want to talk to her, talk to him about her. Maybe he can assess her instead down, down at the nursing.

In the next description a participant described the birth of her child and how this experience affected her trust in health care professionals during the labour and delivery experience. She then went on to describe her experience of going home and how it was her mother who noticed that there was a problem with her child. She felt scared throughout her experience and described how it did not matter to her if the physicians told her that her child would not be normal, she would still care for him regardless of what advice was given to her by the health care professionals:

We weren't in Winnipeg but I had him in Winnipeg at the Health Sciences centre. That's where I had him. And I never, cause I was kind of, I noticed that I had a difficulty. I didn't have like a difficulty of having him when he was born but after when he was born, myself, I was sick and never see him for, I don't know, 2 days, 2 nights. I didn't see him. All I know after when he was born he was crying and he told me, the doctor told me it's a boy and that's it. After that I didn't know why anything and I was sick. And when I went to, when I was in recovery room and when I woke up it was already 2 nights and 2 days. And I didn't even ask. I couldn't even talk as I was all dried up, even my tongue is dry. I can't even move it. I didn't even ask why I was like that, that time. But I thought I knew why this had to cause I had that other problem when I had my second one and after when he was born I was sick. I had blood clots and I didn't bleed. That's when I had my second one. And the third one when I had him, that's what I was. But I was unconscious there for 2 days, 2 nights. And after that when I went to the Maternity ward, I asked where is my baby, you know. Cause I never seen him. And when we're going to bring him and he's O.K. That's what they said. I waited for him and they brought him and I couldn't even touch him. He was on the board. He was ... Not strapped in but he was so sensitive skin like only this, blood comes out.

Even here and here and here. He was all beet skin red. All dried up and they can't touch him. And he was having some kind of meeting here and he told blood ... sensitive and they told me not to touch him. Be extra careful. Couldn't do anything.

But the following day it was. He was getting better rapidly after that. And we stayed there 2 weeks cause of him cause he was very small. And I overdue for, oh, almost 3 weeks and he was small. He was only 6 pounds and a big head. I didn't even notice it until I took him to \_ and I was, I was holding him like that and my mom came in and she says, there's something, it's not right for him. She looked at him. And he was not a big kid and that's when I noticed he had a, starting to have a big head. I didn't even notice that cause I always saw him. And when she walked in my place she told me that something doesn't look right on him. And that he's got a big head. And that's when I noticed. He had they didn't even tell me until when he was about 6 months old. One of the workers at \_ told me you have to go to Winnipeg for an appointment. ... I didn't even ask why. I just went and she came out. And they, they, um, they, the doctor sent him over here and I asked, that's when I first asked, what's wrong with him. And I, he told me, we'll come and talk to you later and I was very scared. I didn't know, I didn't know what's wrong. And only the nurse and doctors came in. They told me he's got a big head and he might have a shunt. A shunt? ... Yea. Cause he's got too much water or air in his head and he's going to have a problem, he says. he told me, you're a very good mother, he says, you have taken care of him real good cause when he was born he could have been retarded, really retarded. He won't be able to sit, he won't be able to. That's what the doctors said too but I didn't even think about these things when they told me your baby might be retarded. He might be, he won't be able to sit, he won't be able to hold his bottle, it'll just lay there on the bed. That's what they told me but I didn't even think about it, I just took him home. But to hold him like that but luckily my mom noticed that maybe he had, he was starting to have a big head. And that's when I asked I was scared then ... wouldn't believe that he was retarded. he wasn't but he's, he's behind his age when he learns. He's about 2, 3 years behind. That's when he started to have seizures too when he almost 2 years old, that's when it started.

This same participant described how when the doctors requested that her and husband sign a consent for a peritoneal catheter to be inserted in their child years later, they were reluctant because of their lack of trust from previous experiences:

I never signed anything. We never signed anything too unless. That's our first time we ever signed something when they wanted to have a catheter in his stomach. That was the first time.

Her husband stated that they did not sign immediately:

We didn't sign it right away.

The mother then reinforced this and stated the following:

We didn't sign right away. We just kept the thing, we think about it and that first time we ever signed anything, that paper.

The father described how it took time for them to accept what the physicians were telling them:

I asked them what are the symptoms or what are the signs of a kidney failure. Then he told me. He, the doctors told me ... about a year. Told us every ... all the things the doctor told me too much. This is where ... but the other, the other families. He touched on one thing you gotta watch, in different areas I've heard of people ... our area was very ... area. You can only get there by air and a lot of people live, a majority of people probably ... and they don't ask for things. ... I told her wait to ask us. Just go ahead and sign the form, the, told what it is communicating with the people from outside. ... She was like, we had the people that don't know nothing, we put ourselves down.

.... He's got to have a teasing ... for a while and had to stop it. And he would never.

The wife summarized what they had just described regarding their experiences of caring for a child with renal failure:

This is what we, what we have experienced, what I told you a little bit about me, the past, when I had him, when he was small. What we do, what we went through. We had a problem and I didn't even ask why and I started for, for the, for the time I'm starting to say no, no, no, when they ask me but ... like that when we have to treat his this and this and that. I'm starting to say no. Have to ask my husband first. That's what I do. And we never sign anything.

In the next description, a caregiver related his inability to trust in relation to their present circumstances. He asked what could be done about his present problem with the heat in their apartment. He then went on to describe how it has caused a dialysis patient to have an infected catheter and how he had assisted this individual by taking them to the emergency department:

The people that are on dialysis, ... they have those tapes, bandages around their chest or over here, and it doesn't stay there. ... Just comes out.

His spouse then described her observations which cast doubts on her ability to trust the health care providers to care for ill individuals with RF, according to what she noticed:

And the thing just coming out and there is pus there.

The father asked the researcher:

So what do you suggest we should do with it?

The wife then described how also their child with RF might have lost trust in the health care providers abilities:

... He was very angry about, I don't know what. ... I said to myself I think it was the heat, get too hot. Again, in the room it was a little bit cooler, he was getting happy.

The importance of trusting health care providers such as the dietitian was evident in this next description given by a caregiver of a child receiving conservative treatment of RF:

So I listened to that dietitian, so she talked to her once and I'll ask her to talk to her again.

A father of a transplanted child revealed one way that he had learned about RF and how he kept abreast of any of the related issues by speaking with the physicians. Although he did not always understand everything, he trusted the health care providers and sought clarification:

Like I always, whenever I come down here I check that bulletin board over there. Check those. But sometimes I don't even understand it. Even when I talk to doctors when I, when \_ was sick here. Sometimes I don't understand anything so I, so I ask them to repeat it. I always. Anything when a doctor tells me, I have to tell him to repeat it again, explain to me real good.

In summary, the caregivers described a variety of situations in which they have learned to trust and distrust the health care providers and have gained information to assist them in caring for their child with RF.

### Learning Self-Care

From the various descriptions given by the caregivers within the context of building strengths, the sub - theme of learning self-care became evident. Most caregivers were able to describe the importance of providing self-care as one of the aspects of caring for their child with RF. Other stories about experiences where caregivers have learned self-care when they had to live through difficult situations were also described.

The first example was given by a father of a teenaged child who had been transplanted and revolved around the issue of self-medication:

Only in the evenings it's pretty hard for him too. Cause when he goes out he has to come home for his pills. If he comes home about 10 o'clock, 10:30, he doesn't go out again cause we don't let him go, eh. He doesn't want to come home. Or else he takes his medications along with him, eh.

He further described his perceptions about the lack of resources for children experiencing RF to learn self-care:

Cause there's nothing over there about renal failure for kids, eh. Nothing over here. Like those symposiums that we come down here, eh. We come down here two times already, eh. ... There's nothing going on for kids with renal failure ...

A grandparent of a transplanted child described how his grandson managed his own care in regards to taking the prescribed medication:

He remind himself. He do it himself.

In the next example the caregiver of a transplanted child worried about the self-care of her child in that she felt there was an increased risk of her daughter being ill just by living on the reserve as opposed to living in the city:

Right now it is, right now it is living on the reserve and she gets sick. I think she gets sick more over there and then she'll here.

One caregiver of a child, on conservative therapy, described how her daughter dealt with a bedwetting problem herself. The caregiver was unable to provide assistance as she was afflicted with severe arthritis herself:

Just once in a while. She wakes up herself when .... When she stayed at her aunt ... my sister ... by herself upstairs ... She wants to do it on her own ... These kids have a bed wetting problem cause I can't even get up for them. Just lay there.

In another example, a stepmother described how her daughter on conservative therapy, managed her own care:

Like she doesn't eat, or eat salty foods or drinks and she ... she's really managing very well.

In the next example a father shared his perceptions of his son's self-care experience of being ostracized by other children initially, but then how he was cared for by the community members. Then the mother described his rare out bursts of anger that they have learned to deal with. The father stated:

But the kids love him very much over there, eh.

The mother affirmed how their son learned to manage himself:

Yea. They talk to him, they, he gets along with everybody. ... At first ... they had a hard time.

The father added more detail to the self-care experience:

That's one thing ... The very first time we were there, he had really, he had a hard time over there. The other kids, eh.

Next the mother continued to describe his self-care:

He'd come home crying and they used to tease him a lot. They didn't want him around cause he was too small. But they accept it now, they really ... Maybe it's because he didn't mind when they called him names.

And he didn't, like he used to have these temper problems but not often, maybe once a year, eh. Remember he did, were you there at the dialysis unit when he got really mad? The nurse was there and was holding onto him. He got mad about his tray.

... he was crying and screaming and they couldn't control him. That time he'd be like ... Probably that's the two times he had it.

The father then described the professional assistance that was given that assisted the child with his self-care:

But he has seen a psychiatrist, eh. He was seeing a psychiatrist at that time. ... Yea that helped for a good, it helped him. And he wanted to see a psychiatrist even, when was that, a couple of years ago, eh? He

told his mom I want to go see that guy that helped me, he says. ... But he had to see a nurse I guess.

When I had asked if this had helped, the mother responded:

Yea. Uh, huh. Depends how much he could talk to somebody that wouldn't say anything about what he's talking about.

Then the father stated:

Not so very much.

In the next example a dyad pointed to a map I had provided and described their ability to provide self-care during a canoe trip that the family ventured on:

Father: We were, uh, 5 years ago, I took to \_ to \_, it's about, oh, round trip would be 500 miles.

Mother: With the canoe, paddling.

Father: Paddling in there. Took us 8 days to get there.

Mother: They were, they followed the

Father: old trail.

Mother: The old trail. But the old trail is

Father: No longer there.

Mother: No. It's just a line to know that you are the ... so they paddled all the way to \_.

Father: It was nice. I enjoyed it.

Mother: Just three canoes, eh. All his brothers ...

Father: We wanted to go to \_ our next trip.

Mother: Yea, \_.

Father: It's somewhere out here. Huh.

Mother: Just, they have an old trail into the old factory because I guess that's where they went with a horse or by foot.

Father: I enjoy those kind of things.

Mother ... we have, even reading book, um, we have a book that, this is the book they made.

Father: And we were working at the schools, we made that.

While sharing their past memories, the above caregivers also described a priest from their community who fostered their community's sense of self-care. The father began by describing the following:

... that priest could have been a millionaire. When he died he said he wanted to get buried in \_ right beside the church and then some of his relatives came over, eh, all dressed up. ... They didn't want him buried there. They came down for the funeral.

Cause I don't, I used to think why did he chose this kind of life. I've always wondered why. And to tell you the truth I think he's one of the more richer than us, living this kind of life he's got more friends than us and a richer life but those who have money, they're not always richer.

The wife of the above caregiver showed me a picture and described how the priest used to provide self-care to the community members:

This is the father. He's pulling somebody's teeth. And he doesn't even use anything to freeze it up or anything. Just pull it right out.

In summary, descriptions were given that revealed how caregivers learned about health care, learned to trust the health care providers and learned self-care. The meaning of surviving evoked memories of past experiences that also gave meaning to the current experience of caring for a child with renal failure, such as going on a long journey. Others that chose to live a "richer life" in a poor

environment were also remembered. These sub - themes fell under the main theme of building strengths, which is what the caregivers have tried to do in order to care for their child with RF.

### The Role of the Family

The next main theme, Role of the family, was evident in all of the descriptions given by the caregivers as they cared for a child with RF. The family network was extremely important in all aspects of caring for the ill child. Whether the family provided company during critical incidents, financial assistance, emotional support, sent food, or offered a place to stay, the family was an important and necessary aspect in the lives of the caregivers and gave special meaning to their personal situation of caring for a child with RF. Under the main theme of the role of the family, two sub - themes emerged: Family Support and Family Members Experience with Renal Failure.

#### Family Support

Family support was evident as the descriptions revealed how the family tried to assist, in whatever way possible, in caring for the ill child with RF. The first example was given by a mother of a child on conservative therapy who described her common law husband's role in providing support:

Ah, he's very supportive. .... he tries to do everything like is there anything he can do, but he can't do anything. There's nothing he can do. Just to be there I guess.

In the next example a single mother described how a nephew provided assistance to her in caring for her three children:

... sometimes my nephew comes and help us out ...

This same mother also described how the siblings responded to the situation and cared for their ill sister during her recovery from transplant surgery:

They understand that she has, yea, they understand. They were in the hospital everyday ...

Family members came to the aid of this caregiver when asked to do so:

Well I just called them. Like when they told me that she was going to have a transplant, I called the house the next day.

Family members also gave on-going support to caregivers by providing them with a place to stay as was evident in this next description:

Well my sister's been helping me, eh, a lot. They're staying at her place right now. That's still too crowded and kids want their own home.

The caregivers would often name the various family members they could rely on for assistance in helping them care for their ill child. In the next example, the caregiver described the support provided by family members, as well as the nurses at the nursing station:

Yea, my husband and my father and mother and the nursing station can, ... come out to help me ... especially my mom's here ...

The caregivers expressed their love for family members. This was evident in their descriptions of the importance of having something to live for:

... We've got, as I said we have two children and one of them is on their own. She's 22. She got married a year ago. Now they have a little baby and we got a lot to live for. And, uh, I think that the more kids that you have the more that you want to live, that's the way I feel.

At times, the caregivers gave their support to family members who had other concerns. In one example, a caregiver described how she advocated on the behalf of her pre-school nephew that she was now caring for, as he had been in an abusive situation:

... got their little boy last week. I am going to see a lawyer today for him. His father was abusing. ... My stepmother was abusing him too. My brother got fed up and told me to keep him.

A caregiver described how he viewed the situation of his sister-in-law, who was considering coming off the dialysis program. The support that this caregiver and his family offered were also described:

... she's approaching her problem differently than us because. One of the reasons why that she lost her husband not too long ago and I says, why go to town, she doesn't want it. She prefers to go ... at first she doesn't want the dialysis. She said, O.K. I'm not having ... She didn't want to live. Says I won't reach that time ... hurt we, just by going through our health problems with him, we, uh, we talked to her and say, well, I'll get it too. It took her a while to accept it. She didn't want to believe that she was one, she had a kidney failure. This is, uh, this is one of the problems that everyone have to face. We somehow tried to help other people like I got an uncle who's on dialysis.

In another example a mother caregiver spoke about missing her family members:

She's 21. She's almost 22. And she's got a little boy already. We haven't seen her ever since he was born. When he was newborn. And they only see us for a few days old when he went home and we haven't seen him yet. But I wanted her to come. She's coming on Wednesday. And I think that. She's, he's 4 months old already and he didn't like people (chuckle) he cries.

The father then stated the following:

We can keep you here a long time talk about families.

To summarize, the family unit had special meaning for all of the participants. In times of need, the caregivers perceived the family as being one of the most important aspects of helping them care for a child with RF.

### Family Members' Experience With Renal Failure

Many of the participants had family members who had had or were presently experiencing RF. The caregivers tried to provide support to the family members and were cognizant of the difficulties in managing the medical condition. Other caregivers had no experience of RF in their families previously.

The first example is a description given by the mother of a child with RF. She discussed an uncle who is receiving hemodialysis and has had to relocate to the city for this treatment:

... he's not feeling good. He's taking a lot of pills like 9 or 10 or more. He just had that on May 30th. He got really sick and all those. That's the first time he got sick. And that when and he found out he had kidney problems but they didn't know what was causing it. They still don't know what's causing it. They're still doing these tests on it. He had biopsy yesterday. So just waiting. It kind of scared him. Like he doesn't know what's going on.

She continued to explain:

From Oxford House. That's where they're from, Oxford House. But he has to move I guess to Cross Lake where there's running water, if he can go back home then. But they won't let him go back to Oxford House but there's no running water there. There's no washrooms just outside toilets. Carrying water, he can't do a lot of lifting.

She also described how the family was trying to assist by donating a kidney:

... cause I found out they said maybe 6 months to 1 year. They might need a new kidney for him. So one of the sisters asked to just donate it.

This next description was given by a caregiver caring for his grandson with RF. He stated that he did not have any family history of individuals experiencing RF and he described his family history as follows:

My dad he passed away when 87 years old. They never sick. He go asleep, that's all.

Some of the participants did not have close family members with RF, or else the family members had died as this next description revealed:

Not close members, no. Like some, like I don't have kidney failure. My cousin had kidney failure but he died already. Not too close to our family.

In this next example, a father of a child with RF described the ill family members that are from his wife's side of the family:

And the other sister, she's on dialysis, she also has ... She's a diabetic.

The wife of the participant above shared the following description about their family members:

... sometimes everybody's in the hospital. Sometimes my sister is in one hospital and my other sister is in the hospital in St. Boniface and my brother is in the hospital too. It go like that.

One participant spoke about the family support offered by those individuals who were knowledgeable regarding the experience of RF:

You know, these the people here that are on dialysis or some sort. They have, they have ways to get around things. They know what to do. They have families to go to and they've been living here and they know exactly what to do.

A caregiver described how most of the adults from their community have died or have never returned to their community:

And I think they all passed away. ... None of them came back to \_.  
Like even those people were transplanted, I think ...

To summarize, the participants shared their descriptions of individuals within their family that had experienced RF, and the meaning of these experiences to them as they cared for their children with RF. Throughout the child's illness trajectory, the family played an important role. Families helped provide some of the basic essentials for health such as food, shelter and safety. They also offered emotional and spiritual support. Awareness of other family members with renal failure increased the caregiver's knowledge and understanding about the ramifications of living with this disease.

### Unmet Needs

The next main theme, Unmet Needs, became evident in the descriptions of the caregivers as they shared their meanings of the experiences of caring for their child with RF. It was within the context of unmet needs that other sub - themes also were described; The Child's Needs, and The Caregiver's Needs. The descriptions of the child's needs centered around aspects of their physical, social, and spiritual needs. The caregiver's needs included various unique descriptions of experiences that were encountered by the caregiver and family of the child with RF.

#### The Child's Needs

The descriptions provided by the caregivers regarding their childrens' needs varied. These descriptions were found to be dependant on the duration and severity of the child's history of illness. There were descriptions that disclosed unmet needs

while at the same time revealed needs that were being met. These were examples of paradoxical findings under this sub - theme of the child's needs.

In the first example, a mother of a teenaged child on conservative therapy described the unmet needs of her daughter with RF which were related to knowledge about her disease. She also described how her daughter had met some of her educational needs about her disease:

She, uh, came to the kidney whatever, some kind of a workshop last year. And my auntie brought her here.

Another example was given by a caregiver regarding her daughter's unmet needs related to lack of knowledge about an impending kidney transplant. She also described her perception of her daughter's unmet needs prior to receiving a kidney transplant in relation to her child's fear about the surgery:

I mean she was, she was scared ... On the day I guess she says to me that she was not ready for a transplant ... she's probably just scared.

Later on, this same caregiver described her daughter's unmet emotional needs regarding her feelings after the transplant and following the father's separation from the mother:

I think she was pretty scared like kind of mad. ... Her behaviour was kind of, it was, uh, kind of bad. ... She was feeling mad and hard to talk to her cause it was only us.

In the next example, a caregiver of a newly diagnosed child with RF described her pre - teen daughter's unmet needs related to her refusal to follow the prescribed treatment. She offered a suggestion as to how best meet the child's needs, by having

advise given by a health care professional as opposed to the parents who have tried to change the girls attitude to no avail:

She would listen. I want to see her grow up and she's too young to have kidney problems especially when she's the only the girl for me. I'm not able to have any more kids.

In an effort to meet the daughter's unmet needs regarding following the prescribed diet, the caregiver tried to use a salt substitute, but this was not to the child's satisfaction:

So we bought her ... she says she doesn't like those things, there's no taste in it, she says.

In regards to trying to meet her daughter's unmet needs regarding buying special food, this was what the mother described:

She just tells me what to buy for her and I go and I don't bring that food for her.

Some of the caregivers, described details about how their childrens' illnesses affected schooling and described this within the context of unmet needs. In the first example, a caregiver described her daughter's education as an unmet need, and related how her child would not pass her grade. She also described how the teachers tried to help meet the child's needs and how her daughter still endeavoured to participate in the school activities:

She won't be passing her grade this year. She missed the school too much. She didn't do her exams since that time she was sick. ... But I guess she wants, still participating all the stuff. She doesn't want to sit back. ... She said to the teacher. That's why they were, put her in a baseball team. She wanted to participate. ... Usually they brought her homework if she doesn't feel good. And send her books home.

Another caregiver disclosed her daughter's unmet needs related to the difficulties she experienced with attending school due to the effects of experiencing RF for the past 3 years:

She hasn't been in school that much for the past 3 years I guess. But she hasn't failed yet. And now I don't know if she's going to pass this year. She's going to school in the hospital and at home with a tutor. Right now just trying to put her on track in school. Like she missed so many. Like she's gotta get up and go to school and get on track again, right. Right now it's not too good.

Another caregiver described her son's unmet needs related to school. Although her child wished to attend, the circumstances surrounding his RF precluded this:

He didn't go to school cause he started on May and he was out of the hospital in June and there was no school until when he had this transplant on September and then he didn't go to school at all ... when he on dialysis. He was ready to go to school with the dial ... , during his dialysis but they phone me and they find a donor, he has it on September 4th or 5, I don't know when, or 6th.

Some of the caregivers described the child's unmet needs as being related to the change in physical appearance. This was seen as being a major factor in how their child perceived the experience of having RF. Concerns about changes in appearance as being an unmet need were voiced by two of the caregivers of transplanted children. Two caregivers of transplanted children felt that this was not an unmet need, but that physical limitations due to the renal failure was an unmet need. The caregivers that revealed concerns about their child's appearance as being an unmet need did not discuss this during the initial interview, but this issue arose during subsequent interviews.

In the first description, a caregiver revealed how, although his child was not concerned with his appearance, he does wish that he could physically do all the things that children his age could do, and this limitation was seen as an unmet need:

Never bothered him really. He told me, he told me so.  
... He only like to do some things that any other kid can do.

The father of this same child also described how his wife wished that their teenaged son would have surgery on his gums as she perceived this as being an unmet need:

And my wife was telling him right now. When are you going to cut your gums off. Well, he said, I didn't make up my mind yet. I was just late. So. Where does it leave him, he's got to tell us anyways, eh, when he wants to get rid of those things, eh.

The mother of a teenaged child who was transplanted described the following example of her child's unmet needs regarding his appearance:

That's what he was saying sort of like that right now. He wants to look the way he did before and he's asking the doctor to do something about it.

The father of this same child then discussed some of the social concerns of their child as being an unmet need:

Some of the problems that he's got is related to his peers. And, uh, his social life is something down the stream he's not, he doesn't fit in the crowd I suppose. He's got to let. What I'm trying to get him to meet other people who have the same problems and they can talk about it. I know that he would never be able to feel like him.

In the next example, the above caregiver described how his teenaged son was upset about his appearance and related this as being an unmet need. He described how his son had considered decreasing his transplant medication in order to try and meet his own needs:

He wants to, uh, he's been talking about that he wants to reduce that program to get back to his normal appearance. And we try to tell him that it doesn't happen. Important to be, you are a good person. ... Yesterday we talked to him and he said, I'm not angry at you guys, I'm just angry at myself. But I can't. By trying is something that you can do, do it, eh. So he'd get frustrated and he wants to yell and he, he hinted I guess he doesn't want to, uh, he accepts that he is sick, he's got to fix it but he tells us the way he see's it.

In the next example, a caregiver who recently separated from her spouse described her transplanted daughter's emotional concerns as being an unmet need:

She was feeling mad and hard to talk to her cause it was only us. Really mad but, I don't know, her father wasn't there for her and just. I been sick too though being alone. Staying alone. He's coming around a bit. I don't know, she just did it most of the time. Probably got tired of it though accepting that she was sick.

The caregiver described the child's concerns with not being like other children her age, in terms of her physical appearance and her stature, as being unmet needs. She gave examples of how her child had unmet needs as she could not meet the height requirements at the Red River Exhibition, and had excessive hair growth. The caregiver also described how she imposed restrictions as she did not allow her daughter to walk too far or go swimming:

Oh sometimes she gets upset but, uh, she doesn't look like normal kids. Doesn't look like normal.

... And she couldn't even go on those bigger rides.

Oh the hair that she grows. And she, I don't let her do anything about that hair. Other kids do. Like she doesn't really like that one. When I say no she wants to do something ...

I don't let her going swimming. ... Or the walk to get one side to another side down that road. ... When she walks around, she gets, she comes home and then she gets real tired and she gets cranky and just say I'm sick.

A caregiver of a child on conservative therapy described an unmet need related to concerns about her daughter's inability to gain any weight:

I asked Dr. \_ about that today cause she can't gain any weight. ... he said maybe it's just the way she is.

In summary, there were many concerns voiced by the caregivers regarding the unmet needs of their ill child. Although the unmet needs that they revealed were not life threatening, they did appear to impact negatively on their perception of their child's quality of life and the meaning that they ascribed to caring for a child with renal failure.

### The Caregiver's Needs

The needs of the caregiver's centered around providing a safe and happy life for the ill child and family. Some of the needs included adequate housing, proper food, employment and recreational activities. At times the unanswered questions caused the caregivers concern and apprehension about the future for their family.

The lack of adequate services was described by the caregivers within the context of their unmet needs. This first example was given by the father of a child that had relocated to the city due to receiving a transplant. During an interview at the hospital, the caregiver described the following:

The only, the only help that we got from Native Services is like translation right here in the building. Other than that just outside the hospital, you're on your own.

Once you are told by a doctor to relocate, automatically the boarding home will look after you. ... the transportation is not provided. It's so people like we didn't know how to go about it, how to go about it and find the, one of the social workers here in the Health Sciences Centre, we have to go and see the social worker and ask for welfare. How do

we go asking for welfare if you don't know? We have never gotten welfare. We have to, we were brought up in a different culture and just the sudden change, just turning the page ... we have to change our lives, change so many ways that a lot of people are afraid for, afraid, scared. Just like you're blank, you don't know where to step. And somebody like us, when we were told to relocate, we had to, we have to be aware we're going to be, to be relocating for a while.

During a subsequent interview the above participant described how their community was experiencing difficulties due to the heat. Another unmet need was the perception that health care providers did not stay long enough learn about the needs of the community and to develop a reciprocal helping relationship:

Well, I think one of the first people I would ask but ... social worker here it seems so hard to get hold of her, the nurses, ... and probably every one of them will say that's too much heat in the room. I would say that try and get some air conditioners for those, for those people. It's not so bad for us but the people here are on dialysis though. ... If you had to act I'd drive her to Emergency. That catheter got infected. It really smells.

But how can we do, how can we look, how do we solve this problem? ... Yea, been bugging her ... She had a dietitian here, uh, ... two weeks ago that was the last day ... We were having problems keeping the dietitian here or the nurse. I don't know why. ... Probably not enough money in there to keep her not long after that. ... Then the money ran out. Now you can take a hike and can't help you anymore. ... That's what's frustrating about it. People that come over to here. Others, they don't stay long enough.

One caregiver of a child who had been transplanted described an important need regarding his concerns about the health care workers at a nursing station in their home community. He described what happened when a physician came to monitor his son:

A doctor came down there for, to see \_\_. And when he saw \_\_, when he looked at his chart, he, uh, he asked for the nurses one by one to come in. Do you know \_\_? Some of them don't even know him. You're

supposed, you're supposed to keep an eye on me all the time, take his blood pressure and there's nothing in his chart.

The only one that knew him was a head nurse and a couple of the nurses that \_ (his wife) was very friendly with, ... That's not very good.

When asked if he felt that the health care workers were scared and didn't want to deal with the situation, he agreed. He then went on to describe how their son was reluctant to go to the nursing station for assistance because they would send him to the city immediately and he disliked leaving his home community. The ability of the community health care workers to provide assistance was seen as being an important need:

Yea, you're right there ... cause it happened to us one time, eh. \_ was, they sent him out right away if he, but he doesn't like to come down here, eh.

Another participant also described how she felt that there was little support from the health care professionals in their community. She identified this concern as being an important need to be fulfilled:

About 2 years he was sick. See how long it takes to make, to know what was wrong with him because the nurses over there when I told, they're not. We knew that when we go there they just don't do anything about it. So something about it or cared to know what was going on. ... Unless when somebody's about to die, that's when they do something about it and somebody get killed. ... He's been sick for so many years, like 15, 10 years and that person is already about to die, that's when they say you have to go to Winnipeg ... Over here when they have a treatment, it's too late to cure it, you know. That person will die or already dying. That's it. That's what they do. Over there.

The spouse of the above participant came to the defence of the health care professionals, and described how the inefficiencies were due to the lack of training of

the health care professionals. He felt that this was an important need to consider that was related to finances:

It's not, it's not their fault that they're not in their studies, they're medical knowledge, they're not fully qualified to find out all the problems. They're only nurses, eh.

And these things that they don't know, the nurses eh, those things that they don't know. Now what you have to do is talk to a Medical Services, Medical Services send them up. There again there's money involved.

A caregiver was concerned about his child's appearance and questioned what caused the distortion among Aboriginal people in particular. He regarded this as being an important need to study:

I don't know if we're doing anything different but when we have those transplant clinics, when we go for an appointment, to compare the white children, you know, they don't seem to have those cheeks puffed out. We have, ... like my son a few more, maybe three other kids ... All their faces have puffed out. And then we get a white kid walk into the room at the clinic, he doesn't have that puffiness now on his face and I asked that guy, did you have a kidney transplant and he said, yea. So what, what did we do wrong?

After making enquiries, to meet his information needs, the caregiver related the problem to the special needs of the Aboriginal people, which he felt still needed to be addressed:

I did my own research too. And that's what I came up with. If you look at that, why is it? Is it because of what our eating habits or diet or what is it? And that's what I asked the dietitian when she came over. The only solution on it. I thought it was because the white people have been eating like that for quite a number of years now, you know, in town. And we just have to turn the page ... our eating habits and our stuff that we eat is totally different. I feel it the same as their drinking. I found out that beer and all the alcoholics are ... in the Aboriginal they react differently than the white. ... And I don't know why.

The father summed up how he felt about his perceived unmet need:

And I don't think the adults really know management of the young people.

A mother with a child on conservative therapy described a need for some kind of educational program that would assist her to learn about health:

There's no, um, there's no any kind of a program to go to about health so I just go on my own.

A parental dyad described the lack of information and knowledge at the nursing station. The father reinforced his earlier statements:

Like I said, there's nothing over there about children's kidney diseases.

When I asked "No information?"

The husband and wife both responded: "No".

Then I asked if they received any pamphlets which gave them any help. The wife responded by saying the following:

I don't think they gave them out.

Her husband reinforced this fact and described how there was only information in the city, not in their community. He also felt that the community health workers had not shown interest in learning about renal failure since they tended to focus on diabetes:

No, nothing over there like that. Not over there anyways. But over here we read those things eh. But not over there. I don't know how much they'd know about those things, like those community health workers over there, eh. Our community health workers cause, like I said, those ... we come down here, they don't even come down.

It would help to tell the other families with kidney failure first time, first time kidney failure, eh. Especially kids. There's lots of adults, but not with kids. You know what I mean. I think there's only, how many kidney transplants, transplant kids there. There's only probably two.

Cause there's lots of adults with kidney, but it's mostly with diabetes there,...

The caregiver of a child on conservative therapy also described her need for more information:

I don't know anything. I never read anything about this problem she has. ... I like reading.

The next example described by a caregiver of a transplanted child related to the needs that were initially being met, then later services were not being provided and therefore their needs were not being met in any consistent manner:

... we had a big argument like that when the ... She asked me how Aboriginals feel about who locate to the city and they start saying to me, Oh, look at, what's her name again?

Look at \_. She can, uh, she did this for us, she did that for us and then she says, you know to be Aboriginal, do you feel like you're supposed to marry, and then she stop. And I say what? Did she marry a white guy. Yes, me. I think so. O.K. Never mind about my question. They were mad about my question. (chuckle)

... we had a nice lady over there who supported us all winter. ... we were learning from her. ... but, uh, they had to let her go. We did, uh, wouldn't sign, you know where you sign your name, petition. Had a petition going and we didn't want to let her go wants her back co-signed it and ... we never heard anything about it. ... now I think we're going to find another one, write another letter that we'd like to have a nurse. But a lot of people that started to believe and they learned a lot from her. That she's one of the caring people I've ever met. I don't know what the other side of the story was, why \_ or the rest of the board don't like her. We should like to know the answer when, or what the reason why they let her go.

In summary, many of the caregivers expressed unmet needs that they had in relation to their experiences in providing care for their child with RF. Others seemed

to feel that their needs were mostly met and did not share any major concerns during my interviews with them.

### Envisioning the Future

The next main theme is entitled Envisioning the Future. Two sub - themes encompassed this main theme; Day by Day and Maybe Tomorrow. The conversations around this main theme varied from being an intense discussion to being a matter of fact passing concern that had not been thought about a great deal.

#### Day By Day

Some of the participants discussed their perceptions of the future of their children with RF as being something which they dealt with on a day to day basis. Although they did not think of a child's future everyday, achieving certain goals such as attendance at school was mentioned. The first example illustrates this perspective from a mother whose child was on conservative therapy:

Sometimes it scares me thinking about her future for her, eh, cause, um, it's hard to just taking one day at a time, to make it better for her in school, trying her, make the best of it. Make her go to trips, I make sure she doesn't miss it while she's still well to go to those things. That's the way I think.

This same mother described how she doesn't worry about her daughter's illness everyday:

Nope. Not everyday but sometimes when I know she's O.K. I don't worry about it.

Another mother described her feelings about her young child that was being followed conservatively:

It's just a relief that the doctor said that he'd be, he's going to be O.K.

When asked if she felt that there was any chance that the illness could reoccur, she responded:

I don't know. Anyway, maybe it's gone.

A caregiver of a transplanted child related his perception of his grandson's healing by describing what his grandson was like day by day as he recovered from his transplant surgery:

Walks good. He very strong already. He walks good and even fat.

Another caregiver of a transplanted child described her feelings regarding the transplant which she did not ever forget about, but chose not to think about every day:

But sometimes, myself sometimes I don't think about it but I never forget.

In the next example a caregiver of a transplanted child gave her perspective of how she felt her child dealt with his illness day by day and described how he learned to live with renal failure:

I don't know how many transfusions in him he had. And the doctor told us too he was lucky to be alive still and he was still walking. It was amazing how he pulled through. He lived to, well he learned to live with it.

The father of this same child also gave his perspective on how their son dealt with RF day by day:

He obviously learned to live with his problems. I don't know how he felt he did. When we were in \_\_ he was always sick, eh. He was always sort of tired and. But he never complained about anything, eh. Just.

### Maybe Tomorrow

The sub - theme label, Maybe Tomorrow, was found serendipitously during one interview with a participant. This caregiver told a story about how his father used to promise a camping trip, and when the children would ask when are we going? he would respond with "Maybe Tomorrow". Thus became the name of a favourite camping place "Camp Wabba" meaning Maybe Tomorrow and, also, this next sub - title. There were other caregivers that spoke about the future that they envisioned and what it meant for them as they cared for their child with renal failure.

In the first example, a mother described her perception of her child's future in the context of maybe tomorrow:

It was pretty hard for me to like, uh, I don't know. Like it was pretty hard but now we're trying to work out on the future and accept that she has kidney problems.

A mother of a child on conservative therapy described the importance of her child's health in relation to the future and what might transpire, within the context of maybe tomorrow. The caregiver described her child's wish to remain healthy, unlike her mother's own health situation:

She doesn't like it. She said, don't like feeling sick all the time. She sees me struggling when I get like this, she doesn't want to get sick too, she says.

The grandfather of a transplanted child related the future to being the ability of his grandson to return home to his community. He also felt that there was a possibility that the future would not last long for his grandson with renal failure, that perhaps maybe tomorrow would not be a likely event:

I think so it's getting better and better every time, that's it. They're trying to go back home and the doctor never let him yet.

It's hard to say. I don't know. ... Some people, some of them don't last long time. That's what I heard.

This same caregiver advocated on the behalf of other Aboriginal people with RF and their need to return home, if only for a short visit, maybe tomorrow. He perceived this as being important to the future vision of any one who has had to relocate because of this disease:

... somebody who's willing, who wants you to survive ... I might be wrong but I think we have to show them that to look forward, to look forward for something and one of the things that I know is every time I go around the community, visiting, people will say, would you like to go home for Christmas, would you like to go home ... And they're always asking will I be able to go home for a couple of days and it so happens that I ask the Kidney Foundation people one time, just last Christmas, and they were willing to do it. But we it took too much time and, uh, that time ... so I approached the band in my community ... they accepted it and just by telling them O.K. your name is on the list there, you're one of the last people that can go for a couple of days. They waited and waited. You could see them that they were delighted could see it on their face that they wanted to go home ...

When asked about his perception of the future, there was uncertainty and hope within the context of maybe tomorrow:

I was talking about it. We were talking about it a few days ago about our future. What kind of future will our son have and to tell you the truth it's hard for us to think there's something like basically what we're going to do next year. I think the reason why I feel that way is I've been working with people that are sick two years now and a lot of them are gone already due to their illness. A lot of them have kidney failure, a lot have heart problems. It seems like about 10 people this year that are gone already and it's, this is the way I feel, what's the point in planning something that will happen in 2 years or even next year. I used to think a lot about doing a lot of things. I used to have long term plans, long term goals. But all that thing went down when we decide on moving to the city. It seems like we have to plan what to

do next now. What do you do from here, you know. ... so our answering you, we don't plan anything out for. ... We don't even bother saying O.K., I'll, look first thing we're going to go home in the spring. Spring. Cause if it doesn't happen, it's going to bug me too much. It's going to hurt. So it's wait till tomorrow and let's see what happens. We have so many things going for us. We used to plan out so many things. There has been a lot of delays, even in a community level.

It seems like we don't, even at a community level, we want to do so much right now. I had about three proposals going just before I came out and all of them are working right now. And we plan to have a new airport there and they're working on it right now and should have a new one there and she's teaching, she's on teaching duty. We had to say good-bye to all of it, hoping that we'll get by there some day and continue our contribution to whatever with the community. We used to have good times there, you know. From the garden ... When it's time to harvest ... everybody that, all the little kids digging the potatoes.

In summary, the meaning of caring for a child with RF was perceived to be a day to day concern, particularly during times when a child experienced symptoms of renal failure and increased illness. The future was envisioned as being meaningful in the sense of having something to look forward to while caring for their child with renal failure, such as a trip home to their community. The future also was envisioned in a guarded but hopeful manner as the caregivers dealt with concerns on a day to day basis. They looked forward to the future and the possibilities it held such as a trip back home to their community or perhaps a return to being near normal, maybe tomorrow.

### Enhancing Power

The participants described solutions and potential possibilities for themselves and for others living through the experience of caring for a child with RF. The focus of this last main theme is Enhancing Power. Within Enhancing Power, there are four

sub - themes; Getting Involved, Educating the Caregivers, Educating the Community and Returning to their Traditional Ways.

### Getting Involved

The importance of becoming part of the solution to the problems encountered by the caregivers of children with RF became evident in my interviews and is the focus of this next sub - theme Getting involved. One of the caregivers described the injustices that the Aboriginal peoples have experienced and provided description regarding the importance of their involvement in decision-making:

We had a meeting which occurred two weeks ago, asking if we can benefits we have either ... and our, at the end, I think ... that we don't have any special benefits at all, you're like us. And any person that moves to the city, go to school. We don't have any other thing. Just like, eh, everybody like one of us. I don't kind of believe in that cause, uh, we have the right, we have rights as an Aboriginal people to ask for, uh, help, eh. But we find out last, 2 weeks ago that as Aboriginal. We don't have those things. We have at least in ... anybody that relocated get a special ... for at least 2 or 3 years. At that time they would be able to manage on their own.

Relocation is a big thing and we, we didn't know what we were getting ourselves into. First of all when were told to move in, where do we live? Where do we go? What do we do? How do we get around? All kinds of questions like that. Who's going to help us? Just that. Who's going to help us? Just finding a place to stay is difficult. We didn't know where to start. We didn't know where to go. We didn't know where to look. And, uh, having somebody to work here and help us, help the family to understand a few things like, or even help them to relocate, that would help. And supporting families to face the problems, get the professionals to talk to the parents, get involved, I don't know what.

This same caregiver described some possibilities for empowering others in their situation:

Like the doctor knew that this person is having a kidney failure, that he's got a kidney disease, maybe there could be an organization or maybe somebody who was ... where they might get care. As long as they know ahead of time what might happen, whether maybe they can ask somebody to, uh, guide them through everyday like even with health education or just the social life. We have lots of problems when we moved down, social problems is the biggest here to. I mentioned that, uh, people with problems they like to have, uh, an answer right away or approach somebody that's got something to make them better or make the pain go away. One of the big things that they grasp, they start drinking and drugs just to get away and for, you know, the other thing and they have to do is to try and get themselves, uh, what do you say, try to get your problems busy.

This caregiver described many ways in which he and his family have become involved in order to empower themselves as they dealt with their everyday lives and cared for their child with RF. This caregiver and his family have moved beyond their immediate experiences with RF and have gone into the community:

Get involved with recreation and that's what we're trying to do. I hear, I knew that, just by watching, people who have problems socially and what are getting here, we got ourselves involved in different programs. We even ask and have a group of family support workers involved, from our community, ... the chief of council gave me the job, volunteer, I work with families talk to them. How do you go about finding a place to stay. ... Trying to, um, food service for elementary.

This same caregiver also described some of the people that he and his family have been involved with. He described how he felt Aboriginal people should be involved:

I think we had a similar problem not so long ago, it was 5 or 6 months ago. The tip of the catheter was infected by my other uncle so they wanted to give him a renal dialysis but he wasn't agreeing and today he still doesn't want it. Um, but I think it has to be somebody who's, who's Aboriginal first, who went through those even if somebody that can coordinate ... how they feel or just by experiencing those problems. I think they would feel comfortable.

I know that there is a lot to do. A lot of other people from back home from our community are scared. You're asking that we notice that kids

need help with the city life and that's where it seems to fall. I think they're reflecting their feelings too. They're people like us. We have to have something. Right now I'm involved with a program ... I'm one of the councillors ... I go to a social worker and I work with the nurses, the doctors, the schools, school divisions, the parents, students. And there's more to come we need more people to work. We're involved in their recreation, we're involved in hockey games. ... We asked for a gym to learn volleyball we play basketball floor hockey. We play bingo.

Just like go out and do it. You can't just sit down in the corner and start crying and feel sorry yourself and kind of all the problems that you encounter throughout the stay in the city, it's gotta, there's a way to survive.

There was also a description given regarding this caregivers world vision of the future:

... I think I got a lot of things for you white people a lot and I too learned a lot from, uh, the people too. But the reason that they learned, anybody can learn. But to me you both have a choice to learn to survive. And you better face the reality, like the world is changing fast as we know it.

He gave his perspective on what he saw was happening at the schools now:

... I tell him at school one and I told her look, kids aren't coming out now ... You know there's hardly any white person coming out, there's Filipino and there's black, there's (chuckle) what happened here? When I was going all whites and I was the only coloured person in the whole school, that's what I mean. There's a change, a big change.

This caregiver's family were involved with activities such as running in the marathon:

Yesterday, people are running the marathon. I was there all day, all morning. I told my sister-in-law my sister came in and two of my brothers-in-laws and my sister-in-law they all ran the marathon. I wanted to run too but I was late.

The participant above was asked to become involved in a number of committees, however he was unable to commit himself at the time as there was too much happening in his busy life of caring for a child with renal failure:

I was asked to be a board member in Dial-A-Life. But then I was asked again at the Kidney Foundation if I could be a board member of it, an Aboriginal representative. ... at that time about six months ago, that time I was always busy and never had a chance to. So I told them, no, I won't be able to do it. The program that we have is the only program in Manitoba ...

To summarize, getting involved was described as the best way to meet the challenges of caring for a child with RF according to one couples' perception.

### Educating the Caregivers

The need to educate the caregivers was described in various ways. The caregivers appeared receptive to the idea of learning more about RF and health in general. The sub - theme of educating the caregivers was described by two participants who cared for a child who received a transplant. They have learned to question the health care professionals about things that happen to their ill child with renal failure.

A mother described how they try to share their knowledge with others:

It's just that what I told you we had the experience from our boy being sick. He was born like that and that first time I didn't even ask the reason why and why is this for when they gave him a shot, you know. What is this for? I didn't even ask why they gave it to him and when I asked them, they go back, because they have this record and they tell me what was happening I guess going on. That's what I do. Now we just. Right now if he goes there I would ask what is this for. Why is he getting this? They would tell me. That's the experience I had. It was kind of our problem ... Well, when I noticed that somebody having problems with this, medical problem, I always ask, I always tell this mom that always ask what's wrong and always ask what they give to

them, what is this for. You know. That's what I started doing when I noticed that and always tell, like my neighbours to ask when they bring their child. I always tell her, make sure you ask your doctor why is this for and to tell you what's going on. I can't go to everyone and tell them to ask.

This next caregiver, who was the spouse of the caregiver above, described how he has learned by asking questions:

I think the way you can help them is by you, professional people, nurses, doctors, social workers. This is how I see it. I guess it's somewhat, this is my opinion, eh, I would just. I've been doing it for a couple of years now, I approach doctors, nurses, ask questions. And I do that I have learned a lot in two years and I think just by teaching, educating.

In another example, this same caregiver reinforced his earlier descriptions about the need to educate the caregivers:

And they have to educate people how to live in the city and how to give them a chance to get used to these problems. Cope with it. Everybody suffers.

This caregiver also described how he was empowered by a Priest in his earlier years when he considered quitting school:

I was 16 when I came to the city. And a lot of things were just my first time and it was really scary and to go to school with all the whites and that just by being in the class, you don't feel you belong there. My grades went down to zero and most of my grades were F's. I wanted to quit but I was looking for help and I approached him and I told the priest, I could talk to him, and he said just a few words. ... He says, look at those people around you, they're all French people and none of them can talk in French and you, you've gotten your own language and you speak English and you're pretty smart. Just by telling me that ... I was just going to walk out of school, I went back in class and I sat down and I said, O.K., I'm just as good as him. So I just, my grades went high too.

The next example was given by the caregiver who had also found a mentor to look up to for guidance in caring for his child:

... we need direction as to how to go about it. And this fellow that I talk about got a kidney transplant when he was 16. Now he's about close to 40 years old. But he was the one, the one that tried giving us guidance. We went to, over to him at his house so gave him all that, the kind of diet or what kind of problems he would encounter through all his life and all that. He helped us a lot.

### Educating the Community

The caregivers recognized that there were problems in their home community in regards to the lack of knowledge and understanding about children with renal failure. Because of this perceived need, some of the caregivers advocated having experienced professionals such as nurses who worked with children with RF, come to their community to provide the necessary education.

One caregiver felt that one must have first hand experience with an illness in order to assist others living through this experience. Another caregiver described how his elders spoke about the plight of the Aboriginals experiencing renal failure or other kinds of diseases.

One caregiver described his involvement in the community, and what the elders had to say about disease. He also mentioned the support that he offered to others with various needs:

Kidney is only one area that we're involved. And that's a big issue that we. There's so much, people like us have to learn. And usually, you know, from our area, when somebody's got a kidney disease or any kind of disease, that the medicine man or our elders can do, they, you know, people die. And I think it's like, you weaken, you know you die and the elders say I don't know ... or healthy ones, eh. That's the weak ones that die. Never hear of a person having a brain hemorrhage,

diabetic or ... uh, or headache. Or I never used to hear ... the reason why. They never knew about it. Maybe some guy had a headache but never really discussed it, why? Or have a heart problem and never think about it. Yea, kidney disease is only one there, like there was two guys that were here. This is the way. They don't we don't knock and when you go to a neighbour's you don't knock. Back home you don't usually knock. Just open the door and say hello and you walk in. One of them is having problems between the diabetic, the small one, and the other one's having problems with his wife. And I was surprised they came over because you had stopped and to ask me if ... and the whole family is ... and he's kind of trying to decide what to do. I told him what I think and tell you. I'm just about ready to leave he says eh. I told him that it would be better if he faces the problem instead of running away. So that's it. That's what he decided. He came back and tells me I'm going to go ahead and I'm afraid to face it but I rather face it.

As one interview ended and I expressed observation of the need to educate the Aboriginal caregivers of children with renal failure. A caregiver then asked me the following:

... are you planning on going to any communities like that?

When I asked if they felt that their community would like to hear about my study, both husband and wife agreed. The wife went on to describe who would tour me around their community and how they would disseminate the information to the community members:

Course the CHR workers, the community health workers, ... that is really good at that. She'd take you around. She's really good. And I'm sure they'd like, uh, you to, um, they'd put you on TV. ... We've got our own TV station.

This next participant felt that the community health workers lacked the knowledge because they have not had personal experience with the types of illness that the people have had:

We don't have community health workers in our communities. But these community workers cannot, have never been involved with health problems themselves. Like they, like for the health, community health worker that we have, most of them, but none of these have any, have never had a, um, ... or things like that. The problem is getting so great that they have to get the right person involved. Right now if I had my way, I would get people like us go to communities like up \_ if you've got a problem here and it might happen to your children or the children's children. Now how do we handle this. We, we tried to have a committee of health workers here in Winnipeg. Now they want to have somebody else from \_. They've never had any problems, just pick a guy because this is the guy, this is the chief, brother, you know, and. I would rather have somebody over here that he's been put in the city and he's got to start solving problems or facing all the things he went through this already and that's the kind of fellow we want to have for this. You tell us what happened to you. Or what we're gaining too. I don't like how they, they're system moves ... hiring and firing because she was leaving, whoever's the chief and ... That's the kind of attitude that we have in there.

This same caregiver identified a need to educate others in the city and described his attempt to fulfil this need:

They wanted to have a fellow from \_ to come and live here and start working on the people ... welfare or something like that. To keep an eye on people from \_ that are living here. How much does he know about kidney disease or diabetic, being a diabetic or ... heart disease. Things like that. What I'm saying that I would like to see somebody to work, you know, like that who had experienced the problems already. ... And they refused my, when I write a letter to them they refused it right away. They still want somebody in to, we haven't seen anybody yet. They touch, this fellow's the right, this fellow's a person I would say to talk to the parents or the child. You got to ask why their son is being treated? Why those medications and what do they do? He's a person that should somewhat consult the people or direct people towards that, take them, like totally different. But you got to face it like change your ways. And when she mentioned about asking questions, she learnt. I wanted her to ask questions, I guess, asking them why did they say that, what is this pill for, and, uh, she found out. They gave her one of the antibiotics, she was allergic and I asked her what is, what is causing this. Can't have time to pronounce it but we found out what it was and, you see what I mean. People don't ask why. Why do they take this medication. On the other hand, we had

some people come to us telling us that, uh, we shouldn't let people push you around when you come to town. It's somewhere they sounded as if they're ready to kill, you know. (chuckle) And the people are close to the city, especially toward south. Oh, south is the people there that are so frustrated, they are ready to kill whoever bugs them, eh. It varies. There's different, depending on where you're from. But from our area it seems like we're, people are shy, they don't want to talk, they don't want to communicate. They don't want to do anything with you. Whatever you say, O.K. that's fine with me.

### Returning to Traditional Ways

In one situation a caregiver initiated a discussion on the importance of their traditional cultural practices. This family described how they were returning to their traditional ways in order to help them deal with the impending loss of their child's transplanted kidney. The father described their experiences:

Do you, uh, do you ever ask anything about the, like, uh, our, how do we say that, our Indian medicines? ... \_ went to see him just last week. Smoke. Two or three weeks ago, ...

Next, the mother spoke about her son being taken to a sweat lodge:

... that medicine man, when he took him to the lodge. ... He told us when he came out, he told us that kidney, that kidney's got a blood clot in it. That his kidney had a blood clot that's why it was failing.

Both caregivers went on to describe what they felt the problem was:

Father: That bad blood, he says.

Mother: He's got bad blood. ... He told us things to do but we haven't gotten around to doing them yet.

Father: Cause my dad, cause he passed away ...

The mother then described the rituals that they had to follow in order to help their son:

We were supposed to have a feast for him. But I never ... he has to do his offerings first and then the feast. We're supposed to invite people. ... And he gave him some medicine. He's supposed to drink it four times a day.

The father described the importance of believing in their practices:

You gotta believe it, ... That's what my dad always said.

The mother confirmed this:

You got to believe in it. For it to work. ... to work. I believe in it.

These descriptions then brought back memories of an unusual occurrence that happened during one of their child's hospitalizations:

That's one of the, one of the other things I'd like to tell you. When \_ wants to go in. ... Intensive care and when you go, everyone wants to see him, ... they thought he was going to go, and we knew everybody that was going on there except only one person we never knew. And the nurse said, there's an old man that came down here. Came to pray. Like we never knew who that man was.

His wife then added:

... a medicine man came here to pray here for \_. He was an old man, he says. ... but we never knew who it was. And we were waiting and waiting for him to come forward cause we have to do some in order for him to get better, we have to do some things like feast and offerings. ... But he never came forward. ... as of today, we still don't know who he was and I don't know any old man. ... He had feathers.

This couple still were unsure about the identity of the "old man with the feathers" but their faith in their traditional practices remained strong, and they continued to be involved with them.

In the next example a couple dialogue about their traditional upbringing and how they were trained. The father described the importance of communication for the Aboriginal people:

The line of communication is a big thing for us. You have to watch communication. Even kids in the classroom. They wouldn't even talk to you. We were raised like that, to not talk. Or the parents talk. Do as you're told to do. The thing that I would like to know as a boy, my mom and dad would say, we can't do nothing. It's usually the whites that are worthy, the nuns and the sisters, the father, the priest and the teachers and the nurses. These are the people that know a lot of things. You are under, under them. That kind of attitude, that's what we. Even at school, never used to ask what is this work or why do this, why do you do that. It's always just this. Even if you don't understand it. Do you understand? Yes.

The wife of this caregiver confirmed this description:

And tell you and people in our age are, you know, our age, they don't even ask anything cause those nuns, they still ... don't ask like at school ...

The father continued to describe:

It's not a two-way communication at all. And you got to break that.

The mother then gave the following example:

And I think, I don't know what's going on. The last time when I was there, I was teaching. And I think it's most of the students that are trying to be boss, like they want to do what they want to do in class. They wanted to tell you what you will do. Not you were a teacher and they'll tell you what to do or they'll say, no, I won't do it cause I don't know, I don't know those things and they don't want to learn. It's not like the way it used to be. Like all the nuns who used to be there. But now they have native teachers.

The father then described the difficulties in having a local person teach:

It's just too bad because when those kids go home, they say, O.K. You know that your teacher she used to do that when he was young and they start talking about teachers. And the teacher happened to be a local person and therefore everyone knows him there. And they give him all the bad influence. I'm against that, this kind of school board ...

In summary, the caregivers felt empowered by getting involved in their community activities and by obtaining education. As they began to learn about health

care, and educate their community, they also describe the importance of the need to return to their traditional ways. Recreational activities such as sports or bingo provided a welcome relief from the day to day stressors experienced. Education served to open the communication doors for the caregivers. It allowed them to ask questions and receive clarification for explanations given by the health care professionals. Thus, they also had input into the daily management and decisions making of the health concerns of their ill child.

### The Meaning of Health and Illness

One caregiver described how the Aboriginals differed from the white people in planning for the future. He described his views on the meaning of Health and Illness:

It seems like your ... about in general Europeans ... they have gardens. They plant different things in there ... Potatoes, carrots, tomatoes and they do things to make it richer. ... They put fertilizer ... they put fertilizer every where. Quite a few to make it richer and then they have cows and ... I guess you know what I'm talking about. They look forward, a little bit ahead for their food. It seems like they've been growing food but our families, they spent just wild we go look for it. ... do anything about it, you just fight your own battle and if he makes it then you eat it. And this, we have a garden every year and, ever since ... we water it once in a while and let it go. And if it grows, it grows. ... I guess it seems like it's tastier and tastes better. Same thing with wild life. Let the fish grow and you eat the fish. And everything's getting destroyed. We're running out of ... To the Europeans, they've been doing this, you know, have their gardens and fertilizer. They have their cattle there, they have their sheep there and they, this is how they managed to survive. ... When you eat it and then ... and years and years and then catch and catch and catch the same diet and finally you. Something. That's what I mean by drinking too. You know, they never had drinking and drinking and their kids ... Well we had, we never had, my family, like my grandfather never had any drink in his life and all of a sudden a drink here and a drink there and it's time to move his body and. Just like turning the page over in a book. Turning the page over. And diet, that's what we're talking about what causes all this diseases diet. Such a short time. Maybe I'm wrong but it's. What can

you do? Go with the flow I guess, eh? Got to learn to survive. Get an air conditioner in. Fancy car and. ... at work, get a job, get employed, give you a car, eh. In our community, I guess, part of your work was the work you've done in regard to your own survival. You come down here and you get a different meaning of survival and it takes money to survive. But ... you have to budget your money, you have to look ahead, how to budget. We never used to plan it that way before at home. And should have something on the table and that's like a, for a family, a farmer does about the same. Get a, to go and get and to fight it. ... the nurses too and here they ask all kind of questions, what kind of problems that affect the people I work in the city the problems they encountered and how to solve the problems and they didn't seem to be anxious to know. But if they're going to do it, eh, what good will it do if it doesn't do any good to us. Right?

The same caregiver described his family and the changes in their diet and then questioned me about my family's history:

Well, for my grandparents, all depends on they had a different, getting the diet. ... diseases like diabetic but other diseases the depends on the diet ... Here and now, ... but it's only a, she said, it's only short time. How about you? Your family's been drinking milk ever since, eating this kind of food like?

### Conclusion

In summary, the caregivers described their repertoire of knowledge, skills and experiences that they have developed over time. They also described the personal meanings of those experiences in their everyday lives as they cared for their child with renal failure.

The use of a phenomenological approach facilitated the description of the meanings of the experiences of the caregivers of children with renal failure. The participants were the co-researchers who told their stories as they had experienced them in their everyday lives. This permitted knowledge about the caregivers perceptions to be acquired.

## CHAPTER FIVE

### Discussion of the Findings

#### Introduction

The findings first will be addressed in regards to the methodological issues. Issues and implications related to nurses and other health care providers will then be discussed.

#### Methodological Issues

The movement from the rigid orthodoxy of the classic empiristic assumptions underlying the scientific method is being recognized (McQueen, 1994; Ray, 1985). There is a need to address sensitivity to special areas of study (Cook & Petit de Mange, 1995; McQueen, 1994). The development of a data base for any science entails detailed description and classification of the phenomena that is related to that science (Brink & Wood, 1989).

The literature concerning caregivers of children experiencing chronic diseases has tended to be focused on the adaptation and coping strategies utilized (Clubb, 1991; Copeland & Clements, 1993). None of the studies which I had reviewed provided descriptions of the meanings that caregivers ascribed to their experiences of caring for a child with renal failure. The use of a Phenomenological method allowed the rich descriptions of the participants to emerge during interviews in an institution or in the community.

I found Phenomenology to be a useful method to address my research problem. It also facilitated communicating with Aboriginal caregivers.

Phenomenology permitted the flexibility to engage in conversational dialogue which then allowed the caregivers to tell their stories in their own manner. For some of the participants, the repeated encounters served to facilitate the rich descriptions of their experiences and also allowed validation of the findings.

There were challenges that I experienced using phenomenology with this sample. Two participants reacted adversely to my probes for more indepth descriptions about their experiences. However, once the questioning was redirected away from the participants, the dialogue continued. Building a relationship with the participants seemed to enhance the breath, depth, and quality of my interviews. The development of a trusting relationship in researching Aboriginal peoples was identified as being important in the literature (Cook & Petite de Mange, 1995; Macaulay, 1994). Prior to my first interview there was an Aboriginal member of the Native Services department at the Health Sciences Centre who interacted with the participant during an informal contact while waiting to enter the interview room. This meeting seemed to help spark the beginning of my rapport with the participant although her teenaged daughter did not make any attempt to become involved during the interview process.

One of the participants in my study was surprised at being asked to participate in my study as he had no time to prepare himself for the questions which I asked. The focus in phenomenology is primarily on meaning rather than content. This has

implications for participants in relation to feelings of preparedness for the interview. Preparation time for a meaning - driven versus a content - driven interview appeared to be of little importance in my study. Regardless of the perceived unpreparedness, the interview proceeded with many rich descriptions being revealed by this caregiver. The above challenges are important issues for communication, in that the ability of the researcher to connect with the participants reality may need to be spontaneous on occasion, as will participants need to be spontaneous. It may also be promoted by having other trusted members of the Aboriginal community involved in providing reassurance and acceptance of the merit of the research being carried out.

Another important finding was the difficulty many of the participants had described in relation to understanding the special tests, treatments and referrals that their children required. This was clearly evident in one situation where the caregiver was unsure what genetics was although she had not addressed this question with the health care providers and had agreed to come in for the appointment. These communication challenges will have an impact on the caregivers as they provide care to their children while coping with the cultural and language differences (Kaufert & O'Neil, 1994). Phenomenology permitted the participants to describe their experiences in words that conveyed the meanings of the various tests and procedures as opposed to trying to use the difficult technical medical lingo that was unfamiliar to them.

During my initial interviews, I discovered that three participants did not meet the "urban" criteria for my study. I chose to continue on with those interviews. It was during one subsequent interview that I found out that one participant did indeed meet

my criteria, since they had resided in the city a number of years ago. I made the decision to include the other two non-urban participants as they had been exposed to the urban health services for a number of years while caring for their child with renal failure. This may be viewed as a limitation of my study due to a selection bias or due to a cultural bias since there is lack of common terminology used to define "Aboriginal" peoples in the literature. It was evident from my findings, that the issues described by the non-urban participants were similar to the urban participants in my study. I therefore made the decision to include their rich descriptions in my study. The flexibility of phenomenology ensured that I could adapt to the unique characteristics of the study participants and I did not have to exclude any important findings due to a rigid research protocol.

The discussions that produced the richest descriptive data centered around general topics such as the community, food and the family as opposed to direct questions about health and health beliefs. This finding was noted in the literature on Aboriginal culture (Feste, 1995; Hagey & Buller, 1983). Research on interviewing Aboriginal people have indicated that the health care professionals are often irritated by the indirect answers obtained and try to steer the conversations away from environmental and lifestyle information (O'Neil, Koolage, & Kaufert, 1994).

The findings of my study revealed that a number of caregivers did not actively pursue health care services following the preliminary symptoms displayed by their ill child. This may have been due to their cultural beliefs about non interference, particularly in two situations where the health care providers related the child's

symptoms to "growing pains". These findings are important in that the severity of the illness may have been accentuated by the time lag experienced while waiting for professional advice and care. The trusting relationship may also have been affected, as the caregivers' concerns were minimized by the health care providers.

The phenomenological method permitted the emergence of the conflicting perspectives of this sample, regarding their health beliefs, to surface. The views of the caregivers revealed the unmet needs during our conversational dialogue. Although there were educational resources available to meet the needs of the caregivers that spoke English as a first language, these were not helpful for the Aboriginal caregivers.

Dietary needs were another area of concern as the perception was that there was a lack of resources to assist with the selection of and preparation of foods. The use of phenomenology permitted the discussion of various issues in relation to the caregivers' everyday experiences to develop, whereas these issues may not have surfaced with the use of a deductive approach.

### Nursing Practice Issues

Nursing care that is culturally diverse is an optimal mode of health care delivery (Gregory, 1988; Leininger, 1991). Nurses must however continue to identify the factors that influence client health beliefs and behaviours in order to provide culturally diverse nursing care (Gregory, 1988). My findings revealed that certain health beliefs of the participants were not discussed with the health care providers and thus may have affected the care of the child with renal failure. An example of this

was the mother who would not allow her child to go for walks as she became too tired and cranky afterwards. Nurses should encourage the discussion of healthy lifestyles within the context of everyday life experiences in order to promote wellness and prevent further illness from occurring.

Hagey and Buller (1983) stressed that nurses are often reluctant to release their authority over the caring relationship. Nurses should attempt to gain a better understanding about the importance of detecting changes in health from the perspective of clients. The participants in my study indicated that there was little acceptance of their observations which were not viewed as being credible by the health care workers in the nursing stations, and thus the trusting relationship was adversely affected. Nurses often do not allow the client to assume responsibility for their own decisions which may be seen as being disobedient with noncompliant behaviours in following the prescribed medical regime. According to Watson (1985), the aim of nursing is to protect, enhance and preserve human dignity.

A lack of understanding during the initial stage of the child's illness was a common finding in my study that was consistent with the literature. Strauss and Munton (1985) found that the information health care providers gave to parents with mentally delayed children was negative and lacked any positive feedback or guidance about what behaviours could be anticipated. The lack of recognition of the parents' roles as caregivers was also described (Clements, Copeland, & Loftus, 1990). One suggestion in the literature was to sketch a diagram of the initial assessment of the family in order to provide a picture of the family equilibrium (Clements, Copeland, &

Loftus, 1990). Most of the caregivers did describe satisfaction with the explanations provided by the specialized health care professionals working in the urban setting and they felt that they could ask questions. One individual did not feel that he was allowed the information that he had requested as he was not worthy of this. This response may have been in keeping with the Aboriginal principle of non interference in which only the most talented and qualified members of the society would be entitled to the privileged information (Brant, 1990). The health care provider who attempts to advise or instruct, may in turn be perceived by Aboriginal peoples as exhibiting bad behaviour. According to the native ethic of non interference, this may be viewed as verbal coercion and the advisor is perceived as being an "interferer" (Brant, 1990, 535).

An important finding in my study was the recommendation from one of the participants to have a contact person available who had first hand knowledge of what may transpire throughout the illness continuum of renal failure. This participant did not advocate that the experienced individual be a health care professional, but that he or she would be someone who was sensitive to the special needs of the Aboriginal families caring for children with renal failure. This finding was in keeping with literature regarding involving Aboriginal communities in developing community based services (Aboriginal Health Unit, 1995; Kaufert & O'Neil, 1994).

Another important finding from my research was the basic survival strategies described by the caregivers. Historically the Aboriginal people have had to survive within a hostile environment (Brant, 1990). Traditionally and currently, group unity

and cohesiveness has ensured that interpersonal conflict among members would not be evident within their societies. Conflict suppression was maintained among the extended family. These practices were described by Brant (1990) as follows:

Non interference, non competitiveness, emotional restraint (including suppression of anger), sharing, the Native concept of time, attitude toward gratitude and approval, Native protocol and the principle of teaching (shaping vs modelling). (p. 535)

The implications for nursing practice are that some caregivers may be in need of supports or services to help them meet the basic requirements of survival in their everyday lives. Nurses must recognize that there may be caregivers who are scared and/or reluctant to admit their needs. The importance of ensuring safety, adequate housing, food and financial security should be recognized. Enabling the family to live comfortably may help reduce the stress of caring for a child with renal failure, which in turn may positively influence the health of the child and family. Health care professionals are often in a position where they can discover whether there are sufficient supports in place for the caregivers to assist them with the challenge of caring for a child with RF.

My findings regarding the initial discovery of the illness as a time of increased needs and disruptions was supported in the literature (Clements, Copeland, & Loftus, 1990; Clubb, 1991; Wikler, 1981). The caregivers in my study described the lack of services and the difficulties experienced due to relocating to a new community. This finding was also consistent with the literature (Strauss and Munton, 1985; Turner-

Henson, 1993). The families which have had to relocate may experience greater needs as they lack their community supports. Nurses can identify the caregivers requiring services and organize a coordinated approach to assist them to meet their needs. Efforts to have services offered to the caregivers in their own language will help ensure that there is sufficient understanding of what may transpire during the relocation experience.

Clubb (1991) described "anxiety and family disorganization" as being inevitable during the time of diagnosis of chronic illness (p. 461-462). Although anxiety was described by the caregivers in this study as they were "living in fear", they also experienced sufficient family support, except if they had to travel to the city alone. This had implications for any decisions which may have had to be made by the caregivers by themselves as medical services would not pay for more than 1 escort.

My findings revealed that the caregivers did not describe experiencing grieving and depression which were two responses described in the literature. These two responses were discussed in relation to the parent's experience of coping with the diagnosis of their child's illness (Strauss & Munton, 1985; Wikler, 1981,). Grieving may have been experienced by the caregivers however their experiential descriptions of the meaning of caring for a child with RF did not reveal any manifestation of grief. This is an important area that needs to be explored further. Only one of the participants in my study described being ill during the initial discovery of renal failure. This illness was, however, attributed to a recent marital separation and not to the child's illness, but it did accentuate the problem. The implications of the findings

are that it is important for the nurse to discover what stressors are impacting on the caregivers. The initial discovery of illness is a particularly stressful time. Adjustment may be difficult. The nurse may need to coordinate other services to help smooth the transition and ensure that the caregivers are supported.

The family has a significant role in the care of the child experiencing renal failure and this finding became evident in my study. Anderson (1987) stressed that there are a variety of cultural systems evident within the professional arena that will influence caring practices. An example of this finding in my study was when a family had to leave their home while in the midst of moving in order to receive a kidney transplant. Later when the child was paralyzed while being mechanically ventilated, the caregiver was frightfully scared and needed to call upon her family for support as she did not understand exactly what was going on. The implications of this finding is that the viewpoints from the professional culture may be different than that of the client and family, and should be discussed in order to optimize the caring relationship.

Two caregivers described coping with their own chronic illnesses of diabetes and arthritis, but did not relate these to being caused by their child's experience of having renal failure. Emotional restraint by Aboriginals has been noted to result in extreme grief responses particularly following separation and loss (Brant, 1990). These grief reactions have implications for health care professionals since the problem may not be evident immediately, but may surface at a later time. Three of the children described by their caregivers in my study had experienced significant

psychosocial problems, with two of them requiring professional support and counselling. The significance of this finding in regards to being relocated to a different community has implications for the availability of family and community supports.

My findings revealed that the perceived experience of caring for a child with renal failure was shrouded by fear of the effects and outcomes of the illness on the child and family. The lack of services in the home community required caregivers and their ill children to have to remain in the urban setting. The implications of this were severe, as caregivers lost their savings, homes, educational and employment opportunities. They then had to rely on the provincial welfare system in order to survive. Helplessness and uncertainty were described by the participants in my study as they managed the care of a child with renal failure within an unfamiliar environment.

The participants identified the need for health promotion and illness prevention strategies which according to their perceptions were sadly lacking in their home communities. The perceptions of the participants were that there has not been any health promotion or illness preventative programs related to renal failure offered by the health care service providers in the rural or urban communities. As the scope of nursing practice expands to include involvement of individuals at the community level in health promotion and disease prevention, nurses must prepare to provide services to diverse groups of individuals, families and communities.

### Nursing Education Issues

Nursing education should incorporate culturally sensitive theory and information in the curriculum. This may assist students to learn about the cultural diversity of the clients requiring health care services, and to use appropriate assessment, intervention and evaluative techniques in providing care. The biocultural, psychosociological and linguistic diversities among multicultural populations are important aspects to consider in order to assess clients accurately (Giger, Davidhizar, & Wiecezorek, 1994). The culture of every human being is unique and must be respected. This aspect is germane to understanding and recognizing the importance of and need for transcultural nursing education and transcultural care.

A number of the caregivers in this study expressed that they wanted more information and they wanted to have their questions answered by the health care professionals in the city. These individuals did not trust the health care workers in their own community since they felt that they lacked knowledge and often just sent them to the city anyways. Priority was not given to the caregivers' needs for information and reassurance according to their perceptions. The necessary supports in the home communities were often described as being insufficient. Both of these issues are reflective of the lack of changes in local control and culturally sensitive Aboriginal health care services (O'Neil, 1993; O'Neil & Postl, 1994). The lack of educational opportunities for Aboriginals has impeded those wishing to become involved with providing health and social services (O'Neil & Postl, 1994).

The findings of my study indicated a great need for educational support of the children experiencing renal failure. This issue was further validated in the literature which indicated that one of the major concerns of educators today was the poor success rate of the urban Aboriginal students (Kehoe & Echols, 1994). They suggest that in order to meet the special needs of Aboriginal students, their traditional cultures must be recognized. It was reported in a Winnipeg study by (Clifton et al, 1992), that Canadian Aboriginals were rated low on a semantic differential measure of intergroup attitudes towards the Natives [sic] by junior high school students from seven ethnic groups (as cited in Kehoe & Echols, 1994).

Grondin (1989) argued that ethnicity is often used as an "abusive" argument in research of the Inuit, and that the problems they faced are dealt with just the same as anyone, anywhere (pp. 35-36). Gregory (1988) stressed that the caring practices of the nurse as the primary health provider were instrumental to the provision of holistic care to Aboriginal clients. By encouraging the use of traditional practices, clients would be able to preserve and develop their health values. Garro (1988) described health care providers as being one of the main sources of the shared cultural knowledge related to chronic illness in the Aboriginal communities.

Information about community education and community involvement should be incorporated into the curriculum in order to foster learning about community development.

### Nursing Research Issues

Qualitative research methods and techniques are seen as the strengths of cross-cultural research studies. It would be interesting to repeat this study with other populations of varying ethnic and cultural backgrounds using a phenomenological approach. This would serve to reveal any differences in their values and beliefs in order to provide further baseline data to the experiences of caregivers of children with renal failure. Research on the child's perceptions of their experiences of living with renal failure would also be helpful to provide information to health care providers. The experience of the siblings of children with renal failure is another area of research that needs to be explored.

Research on the biocultural ecology within the Aboriginals living in the urban setting, the rural setting and on the reserves would be helpful. This type of research would integrate culture, human biology and ecology and may reveal findings that would contribute to a primary health care data base on Aboriginal people. This would then enable health care providers to base their care on findings other than the normative, medically oriented Caucasian data that are currently available (Giger, Davidhizar, & Wiecezorek, 1994).

Another important finding in my research was a caregiver's question of the biological variations in the Aboriginal population as being an area in need of further research. The literature suggested that culturally appropriate nursing care is difficult to provide without the knowledge of biological racial differences (Giger, Davidhizar,

& Wieczorek, 1994). The exploration of biocultural differences that may be evident among Aboriginal peoples is an important area that needs to be researched.

### Health Care Delivery Issues

#### Insiders versus Outsiders

The caregivers in my study used health care services from both the expert "outsiders" located in the urban setting and the "insiders", the health care providers located in the rural community setting. The caregivers revealed that although they lacked faith in the knowledge and skills of the local health care providers within their own communities, they also disliked travelling to the large urban centres. For acute care services, the participants would rely on the urban health care providers and preferred to receive services from the specialized professionals. The significance of this finding is that there is a lack of support for the caregivers in their home communities, and there are large costs involved with having services provided in the acute care setting. The financial costs of transportation as well as the detrimental effects on the family and social networks indicate that a different model of service delivery must be put in place in order to meet the needs of the caregivers and the service providers. Awareness and acceptance of the cultural diversity among families are important considerations for health care providers (Kaufert & O'Neil, 1994; Keltner, 1993).

The survival and the persistence of the Aboriginal caregivers stems back to the traditional approaches that the Aboriginal peoples have used in order to allow healing to occur. As O'Neil (1993) explained, the traditional approaches have with stood the

test of time despite the many social challenges faced by the individual and communities. The caregivers have learned to manage the care of their ill children in ways that were unique to each individual and family. The diversity found among Aboriginal people with a common illness is not unusual and has been noted in the literature (Cook & Petite de Mange, 1995; Garro, 1995). Garro (1995) advocated the need for health care providers to respond to society's involvement and responsibility as well as the individual's role in the provision of health care.

Following interviews with Aboriginal individuals in an Anishinaabe community in Manitoba, Canada, Garro (1995) reported how people accounted for their own diabetes and the increase of this illness in their community. Contact with an Anishinaabe healer was rarely done if prior consultation had been initiated with a physician. My findings differed in that two caregivers divulged that they had sought the services of a healer. This was, however, done in conjunction with ongoing follow up by physicians in the city. This finding was supported by the literature (Gregory, 1988; Grondin, 1989; Waldram, 1990).

Waldram studied the Aboriginal people and their use of traditional medicine in urban areas. He concluded that traditional medical services continue to be used for reasons unrelated to utilization difficulties or financial problems with the use of western services. The data suggested that the socio-economic position was less significant than the importance of retaining their traditional culture.

### The Paradox of Story Telling

Another important finding in my study was the use of story telling. The caregivers attempted to reveal the issues surrounding their everyday lives through the vivid descriptions of their experiences. The use of story telling has been considered to be useful in providing education to individuals experiencing chronic illnesses such as diabetes (Feste, 1995). It allows individuals to connect with their own stories and to relate them to similar everyday experiences with life. The integration of the chronic disease into the individual's life helps to overcome barriers, may foster personal acceptance and help to identify the resources available. As mentioned previously, it was important in my study to not refer to the descriptions given by the participants as being "stories", as this may have guided their perceptions of a make belief story as opposed to a true life event.

Storytelling is an important aspect for health care providers to understand (Aboriginal health unit, 1995; Feste, 1995, Hagey & Buller, 1983). Aboriginal people believe that the stories contain the words of their ancestors. Stories include their cultural values, relationship with the land, and relationships between people. The stories educate the Aboriginal children and keep their spirit alive. The importance of actively listening to the Aboriginal stories is an art which should be understood and could be learned by the health care providers since it is part of the Aboriginal culture. Being Polite, and not interrupting, are crucial to developing therapeutic relationships with Aboriginal people. This was an important consideration in my study as none of the participants spoke English as their first language.

The technical medical language also made the participants in my study uncomfortable. This finding is significant as the use of medical language may cause caregivers to be reluctant or to not question the health care providers about certain issues. It was evident from my findings that those individuals who had more experience with receiving health care services were less reluctant to ask questions.

These findings have implications for the health care system. It is important, in health care delivery, to ensure that time is given to allow the Aboriginal caregivers' to express themselves when telling their stories. It is also important to schedule time for discussion and to encourage the caregivers to ask questions.

#### Nutritional Needs

The implications of my findings regarding the nutritional needs of my participants are that the Aboriginal caregivers living in the urban setting would benefit from intensive education regarding the special diets needed to care for children who are experiencing renal failure. There was little satisfaction with our western diet, and the Aboriginal caregivers expressed their dislike of such things as lettuce and salad. The use of indigenous plant foods in the diets of Aboriginals have important health implications (Kuhnlein & Turner, 1991). The replacement of many of their natural foods with purchased foods has led to a decline in the quality of their diets. The participants in my study spoke about their nutritional concerns due to their difficulties in adjusting to their perceptions of a rigid, unpalatable diet that was specified for their child with renal failure.

The health care providers that I spoke with regarding this identified problem acknowledged that the main problem was the obesity amongst the children with renal failure and the inability of the Aboriginals to conform to the specified diet. The literature supports this as being a major problem among the Aboriginal people (Houlden, 1994). A dietitian that I spoke with felt that the diet of the children with renal failure was much more lenient than that of adults with this illness. It was also felt that gathering recipes for the Aboriginal clients would be a good project for student dietitians.

Recipes containing the various types of Aboriginal foods commonly used could be made available. Buying and cooking sessions in their homes may assist the caregivers in learning how to prepare acceptable, nutritious meals for their families.

The research findings have implications for health care delivery as the emphasis has moved to the provision of community based services. The lack of community based resources and services were clearly described by the participants in my study. These findings are further supported in the literature. A study was done by the Medical Services Branch of Health Canada, regarding the planning of services for natives [sic] in Moose Factory Zone, Ontario. The intent was to develop a proposed satellite dialysis unit in Moose Factory (Wilson, Krefting, Sutcliffe, & Bussel, 1994). It was found that there were indications that the Native [sic] clients would not trust the local medical staff and therefore would not tend to utilize those services. This finding has implications for public and nursing education in order to provide the necessary information to consumers so that they can make informed decisions

regarding their health concerns and needs. These findings also indicate a need for the dissemination of current information and the provision of continuing education to the health care providers in the remote areas of the province of Manitoba. The delivery of services in the community by experienced health care providers was identified as an important need of the caregivers of children with renal failure.

## Conclusion

This topic was an important area of nursing research for a number of reasons:

1. There was no literature available on how urban Aboriginal caregivers perceive the experience of having children who suffer from RF.
2. End stage renal disease has been identified as an excessive burden among Canadian Indians [sic] (Young et al., 1989).
3. Health care professionals may be assisted to provide effective individualized health care when addressing health concerns of the caregivers.
4. Education provided prior to dialysis or transplantation has been shown to delay the starting of maintenance dialysis (Binik et al., 1993).

A phenomenological approach contributed to the conceptual base of nursing through the exploration and description of the experiences of caregivers. A phenomenological approach required concentration on the meaning of these experiences. This approach facilitated description of experience as opposed to defining, categorizing, or explaining it (Oiler, 1986). Phenomenological approaches have, as their end, pure description of meaning, rather than explanation of cause.

The essence of the meaning of caring for a child with RF was revealed through the caregivers' descriptions of their everyday life experiences. Their world revolved around their children. The threat of recurring or worsening illness necessitated the caregivers' constant vigilance. Although the illness was not thought about all the time, it was never forgotten. The effects of the experience were far reaching and impacted upon the entire family and community support networks.

Reassurance was felt by the caregivers when they had their questions and concerns addressed by health care professionals in the urban centres, whereas there was little confidence in the capabilities of the local community health care providers.

Caregivers enjoyed being part of the plan of care for their children and were willing to learn and share their knowledge and experiences with others. They foresaw a need to incorporate their traditional ways into a primary health care model of service delivery.

Many individuals are attempting to provide assistance to the caregivers of children with RF, however, based on my research findings, there are concerns that still need to be addressed. The following recommendations should be considered in order to begin to address some of the needs of the caregivers:

1. All communication with the caregivers should be provided in terms which are easily understood. Any technical medical language needs to be simplified and related in ways which allow the caregivers to become informed, to be actively involved in their child's care and to enable them to ask questions.
2. Interpreters should be available and their services should be offered to the caregivers at every encounter with health care professionals. The interpreters should become familiar with the tests and procedures which are commonly provided to children with renal failure so that they can provide useful information to the caregivers. The interpreters could acquire this information by spending time with the nephrology health care providers. As well, the interpreters could share their knowledge about Aboriginal culture and traditions with health care professionals.
3. Culturally appropriate educational tools need to be developed. The tools would then assist the health care providers to teach the caregivers about RF in a culturally sensitive fashion. This would help the caregivers to learn about RF and understand how renal failure may affect their children. In addition, any tools which were developed could be used by interpreters and/or community health representatives (CHRs) to help

reinforce any teaching provided about renal failure in the acute care setting or in the community.

4. Adequate resources need to be provided to the caregivers to enable the caregivers and families to live comfortably. Appropriate housing is an important basic need which should be provided to the caregivers and the families of children with renal failure.
5. Healthy and affordable food must be made available for individuals and communities. This is essential to maintaining the health and well being of the caregivers and families of children with RF and to prevent any further illness from occurring.
6. Community members should be empowered by providing teaching and involving them in learning about healthy lifestyles through community development. Culturally sensitive health promotion and illness prevention programs need to be provided to caregivers and families of children with RF.

In conclusion, my data revealed some information that previously was not found in the literature. The meaning of caring for a child with renal failure, as described from the perspective of the urban Aboriginal caregivers, encompassed many different dimensions. Data from my study revealed the health practices and life skills that the participants have developed in order to manage the care of a child with Renal Failure. The knowledge gained from my study may assist health care professionals in their understanding of the issues facing Aboriginal caregivers of children with RF. My study also revealed how health care professionals better may provide assistance to help the caregivers manage the care of their children. Suggestions for how the Aboriginal caregivers of children experiencing renal failure may be incorporated in the planning of self care in order to maintain cultural values and beliefs were also explicated.

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Table 1

## Comparison of Qualitative Research Methods

| <b>Research Method</b> | <b>Purpose/<br/>Focus</b>                                      | <b>Sampling/<br/>Data</b>                                      | <b>Data Gathering</b>                                                                                                                                                 | <b>Data Analysis</b>                                                                                                                                         |
|------------------------|----------------------------------------------------------------|----------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Grounded Theory        | Develop theory<br><br>Attention on interaction process         | Number may vary per ability to saturate theoretical categories | Interviews unstructured<br><br>Theory develops throughout grounded theory process                                                                                     | Interviews are tape recorded<br><br>Field notes<br><br>Memoing<br><br>Constant comparative analysis                                                          |
| Ethnography            | Explore the local social and cultural world of a certain group | Sampling focus is on the culture                               | Field research<br><br>Researcher directs interview<br><br>Observation in the cultural scene<br><br>Identification of significant meanings<br><br>Structured questions | Units of analysis<br>cultural context<br>Aggregation of data<br>Transformation of data<br>Applicability of data in context of research, theory, and practice |
| Phenomenology          | Explore and describe phenomena                                 | Sampling to obtain sufficient description about experience     | Participants-co-researchers<br>Semi-structured and informal interviews                                                                                                | Aim is the description of experience<br>Colaizzi, (1978)                                                                                                     |

## Appendix A

### Ethical Considerations

The Ethical Review Committee, Faculty of Nursing, University of Manitoba reviewed the study proposal. Upon receiving approval from this committee, a letter requesting access to the study participants and involvement of the health care providers was submitted to the HSC.

After approval from all sources, a verbal and written explanation of the study was offered to all participants. The confidentiality of the participants was maintained during the selection process by having the clinic nurse ask the potential participants if they wish to have their name given to the researcher. After the researcher explained the study, the potential participants were given the opportunity to ask questions and to seek clarification of any issue or concern related to the study. When the consent had been signed, a time was arranged to conduct the tape recorded interviews. If participants were willing to be interviewed immediately following signing the consent, this was done. The tape recorder and the interview session was stopped at any time if the participant wished to do so, or if a health care professional requested time with the participants.

Those participants who were interested in participating were the only ones known to the researcher. Their identity was coded by number and their names were known only to the researcher. My thesis committee and I had the only access to the data collected. The information obtained will be kept in a locked filing cabinet by the researcher for seven years following the study. The tapes were transcribed by a secretary who was not aware of the participants' identities.

#### Obtaining consent

For my first two interviews I started the tape recorder after the consent had been signed. Following this, I started the tape recorder immediately upon entering the room, and left the tape recorder on after the interview as I found that there was data that I was missing by waiting until after the consent had been signed, or by turning the tape recorder off right after the interview. This may also have served to decrease the participants' attention on the tape recorder during the interviews as well as ensuring that all the information was captured prior to the consent being signed, during my explanation of the consent, and following the interview. I casually asked the participants about the trip to the unit that day as I set up my tape recorder and microphone and arranged the consent forms and the demographic questionnaires. I showed the participants the consent form as I went through it with them and then had them sign it. Initially I completed the demographic form, hoping to put the participants at ease, and I was also trying to expedite the interview process. Later, as I realized that I was not giving the participants a chance to write their responses, I

chose to allow my last two participants an opportunity complete the demographic form. I then realized that this was a difficult task for these individuals due to their difficulty with reading and writing in English. There was one participant who asked numerous questions about the study, requested copies of the consent form and explanation of the study, then stated that this would be discussed with the child and that they would contact me if they were interested in participating, which they did not. There were no other refusals to participate, to be tape recorded during the interview, or to be re-interviewed. On one occasion, a participant refused to be interviewed without having their partner present. All the participants except one requested a copy of my final report.

## Appendix B

### Explanation of Study to Health Care Providers

(What the researcher says, and/or letter given to health care providers)

Hello, my name is Nadja Schulz and I am a registered nurse and a masters of nursing student at the University of Manitoba, Faculty of Nursing. I am conducting a research study as part of my thesis. I am interested in finding out about the experiences of urban Aboriginal caregivers of children with renal failure.

Since there is little known about urban Aboriginal caregivers of children who have renal failure, more information is needed to better understand how to assist urban Aboriginal caregivers to provide care to their children.

I will be onsite during the data collection phase of my study, and I am requesting the clinic nurses to identify and approach potential participants for the study. I will be interviewing participants 1-3 times for approximately 1 hour. The knowledge that is obtained may help Health care providers to better understand the needs of urban Aboriginal caregivers.

If you would like further information please contact me at

Sincerely,

Nadja Schulz

### Appendix C

**Request for Permission to Release Names of Potential Participants**  
(Used by Health Science Centre Clinic health care professionals when approaching caregivers)

Nadja Schulz is a registered nurse and Masters' student from the Faculty of Nursing, University of Manitoba. She is doing a research study about the Aboriginal caregivers of children with renal failure.

The information that is given is strictly confidential. Whether or not you decide to participate will not affect the care or services you receive in any way.

Mrs. Schulz would like to talk to you and tell you more about the study so that you can decide if you would like to participate. Would it be alright with you if I give Mrs. Schulz your name so that she can explain the study to you?

(If agreeable, the name of the potential participant is given to the nurse researcher and the clinic nurse thanks them).

(If the potential participant declines, the clinic nurse thanks them for their time).

## Appendix D

### Explanation of Study to Potential Participants (what the researcher says to potential participants)

#### The Meaning of Caring for a child with Renal Failure: A Phenomenological Study of Urban Aboriginal Caregivers

Hello, my name is Nadja Schulz and I am a registered nurse and student in the graduate nursing program at the University of Manitoba. I am conducting a research study as part of my thesis. This letter is an invitation to participate in my nursing research study. I am interested in finding out about your experiences of looking after a child with renal failure.

There will be 1-3 times that I would like to meet with you for approximately 1 hour to hear about your experiences of having a child with renal failure. I will first ask a few questions about you and your family. Then, I am interested in finding out about your experiences of caring for your child with renal failure.

You are not under any obligation to participate in this study and you can stop the interview at any time you wish. The information that you give me will be confidential and your name will not be known to anyone except myself. Being a participant in this study will not affect the care or services that you, your child or family will receive.

There will not be any direct benefit for you in participating in this study except that you will have the opportunity to share your experiences and in so doing, you will help nurses and other health care professionals in understanding what it means to be a caregiver of a child who has renal failure.

Would you be interested in participating in this study?

(If yes, then present consent form)

(If no, "Thank you very much for taking the time to listen to me.")

## Appendix E

### Consent Form

#### The Meaning of Caring for a Child with Renal Failure: A Phenomenological Study of Urban Aboriginal Caregivers

In signing this document, I am giving my consent to be interviewed by Nadja Schulz, a Registered nurse and a student of the University of Manitoba. I will be part of a research study that will focus on the meaning of kidney disease to the parents of children with renal failure being seen in the clinic at the Children's Hospital or the transplant clinic. This study will provide some guidance to people who are trying to help parents and their children.

I understand that I will be interviewed at the clinic in the Children's Hospital or the Transplant clinic while there for a scheduled appointment, or at my home if I choose, at my convenience. I will be asked some questions about my child's kidney disease and my understanding about it. I understand that my name will not be known by anyone other than the researcher, and that I may choose not to answer any questions. I also understand that my child may be present during the interview.

I understand that I was chosen to participate in this study because I was chosen from a group of urban Aboriginal caregivers of children with renal failure. This study has been approved by the Faculty of Nursing Ethical Review Committee, University of Manitoba.

This interview was granted freely. I have been informed that the interview is entirely voluntary, and that even after the interview begins I can refuse to answer any specific questions or decide to stop the interview at any point. I have been told that my answers to questions will not be given to anyone else and no reports of this study will ever personally identify me in any way. I have also been informed that my participation or nonparticipation or my refusal to answer questions will have no effect on services that I or any member of my family may receive from health or social services providers.

This study will develop a better understanding of the meaning of kidney disease to caregivers of non Aboriginal and Aboriginal children with kidney disease. However, I will receive no direct benefit as a result of participation. The information that is collected will be kept secure for 7 years after the study and will then be destroyed.

I understand that the results of this research will be given to me if I ask for them and that Nadja Schulz is the person to contact if I have any questions about the study or about my rights as a study participant. Nadja Schulz can be reached through a local call at

The name of the research advisor is Professor Pat Farrell. Pat Farrell can be reached at

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## Appendix F

Demographic  
Questionnaire  
(given to participants by the researcher)

- Date: \_\_\_\_\_
1. Age in years: \_\_\_\_\_
  2. Sex: M \_\_\_\_  
F \_\_\_\_
  3. Educational Background: \_\_\_\_\_  
Type of Education: Formal \_\_\_\_ Informal \_\_\_\_  
Number of years: \_\_\_\_\_ Grade: \_\_\_\_
  4. Language spoken: \_\_\_\_\_  
Place of Birth: \_\_\_\_\_
  5. Residence: \_\_\_\_\_ Number of Years: \_\_\_\_\_
  6. Employment: \_\_\_\_\_
  7. Family members: Spouse or mate: Y\_\_ N\_\_  
Number of Children: \_\_\_\_  
Others: \_\_\_\_\_
  8. Others in family having Renal Failure: \_\_\_\_\_
  9. Number of years experience as caregiver of child with Renal Failure: \_\_\_\_\_

## Appendix G

INTERVIEW GUIDE  
(Used by the researcher)

The study will use the following interview questions:

1. Can you tell me how you felt the first time that you were told that your child had renal failure? Probe:  
Can you remember who told you, what did they tell you about renal failure?
2. Overall, what has it been like for you, having a child with renal failure? Probe: how has it affected your everyday experience, ie, your day to day experiences? Probe: morning, afternoon, evening, night, special events
3. How has it been for your family? Probe: how has it affected their everyday experience, ie, their day to day experiences? Probe: morning, afternoon, evening, night, special events
4. Tell me about some of your daily experiences in caring for your child with renal failure? Probe: do any stories come to mind?, special events
5. Can you tell me some of the things you have had to do differently to care for your child? What has this been like for you? Probe: morning, afternoon, evening, night, special events
6. What do you believe or understand about kidney disease? Probe: What has this meant for you as you care for your child?
7. How have you learned this? Probe: people, media, stories from or about others
8. Do you know or have you heard of anyone else who has kidney disease?
9. If "yes" to #7, What have you learned from them (eg. what works, what doesn't work, any stories?) that you use in caring for your own child?
10. How severe do you believe your child's sickness is?
11. What does this mean for you? For your family?
12. What do you think about the treatment your child has received? Probe: procedures, professionals, lay people, access to resources

## INTERVIEW GUIDE (continued)

13. What has this treatment meant for you? Probe: procedures, professionals, lay people, access to resources
14. Can you tell me about the special things that your child must do as a result of having kidney disease? Probe: special foods, drinks, restrictions
15. What does your child believe about the need for these special things? What do you say to your child about the need for these things? Probe: special foods, drinks, restrictions
16. Can you tell me any stories about how your child is able or not able to follow these special restrictions?
17. What has it been like for you to have to follow these everyday? For your family? Probe: How do you have to adjust your schedule, etc... .
18. Can you tell me any stories about how your family is able to, or not able to adjust?
19. Are there any things you will have to do in the future for your child in order to care for his or her health needs that you don't have to do right now? What will this mean for you?
20. How does the rest of your family understand this sickness? What do they believe about it? What meaning does it have for them? Probe: each family member or significant other, re their understanding and beliefs about this sickness.