

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

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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.

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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