

PATIENTS' PERCEPTIONS OF THEIR EXPERIENCES
WITH END-STAGE RENAL DISEASE (ESRD) AND
HEMODIALYSIS TREATMENT

CENTRE FOR NEWFOUNDLAND STUDIES

**TOTAL OF 10 PAGES ONLY
MAY BE XEROXED**

(Without Author's Permission)

DEBORAH M. GREGORY



INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

Bell & Howell Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
800-521-0600

UMI®



National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisitions et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file / Votre référence

Our file / Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-47421-6

Canada

**PATIENTS' PERCEPTIONS OF THEIR EXPERIENCES
WITH END-STAGE RENAL DISEASE (ESRD) AND
HEMODIALYSIS TREATMENT**

by

Deborah M. Gregory

A thesis submitted to the
School of Graduate Studies
in partial fulfilment of the requirements for the
degree of
Master of Science (Medicine)

Faculty of Medicine
Memorial University of Newfoundland
February, 1998

St. John's

Newfoundland

DEDICATION

This thesis is dedicated to my sister, Cynthia (Farrell) Misch, who has displayed profound courage and faith in her battle with cancer. While writing this thesis she provided me with an increased understanding of the meanings of living with a chronic illness. The challenges of dealing with the many fears and the accompanying uncertainties and living in hope for a better tomorrow can be captured through her illness and treatment experiences.

The beginning of wisdom is: get wisdom;
at the cost of all you have, get understanding.

Proverbs 4:7

ABSTRACT
PATIENTS' PERCEPTIONS OF THEIR EXPERIENCES WITH END-STAGE
RENAL DISEASE (ESRD) AND HEMODIALYSIS TREATMENT

To explore patients' perceptions of their experiences with ESRD and hemodialysis treatment, 71 interviews were conducted with 36 adult patients established on dialysis. The sample was equally divided by gender, with 78% over 50 years ($M = 57$) and most on dialysis for ≤ 3 years (72%). Using a grounded theory methodology and a constant comparative method of analysis, a theoretical model was developed which suggested that patients' perceptions of their experience revolved around three constructs. These include redefinition of self, quality of supports, and meanings of illness and treatment and are linked by "critical turning points" which facilitate or impede quality outcomes. The emerging theory suggests that a "new sense of self" is an emotional/psychological state that fluctuates with the evolving meanings of illness and treatment (acute/chronic illness, treatment effects) and perceived quality of supports (health care providers, family and friends, dialysis peers, dialysis environment). The findings indicate that when confronted with this new way of being-in-the-world, the individual becomes cognizant of an uncertain future, continued dependence on life-sustaining technology and the expertise of health care providers, and the demands upon and sacrifices incurred by significant others. All aspects of patients' experiences with ESRD and hemodialysis treatment must be considered if health care providers are to facilitate positive health outcomes.

Conclusion: Patients' perceptions of their experiences on hemodialysis revolve around the psychological adjustment to illness chronicity, the quality of supports (particularly in facilitating this adjustment), acceptance of treatment regimes, and the tension between desired and expected, and the actual treatment outcomes. The perceived experience may influence the quality of outcomes.

Key Words: hemodialysis; grounded theory methodology; quality of outcomes; patients' perceptions.

ACKNOWLEDGEMENTS

I would like to express sincere appreciation to the hemodialysis patients who enthusiastically shared their thoughts and feelings during our interviews. Your willingness to participate in this research project allowed me to gain a valuable insight into the total experience of living with ESRD and hemodialysis.

I would like to thank the co-investigators on the larger, more encompassing research project of which this thesis is one offshoot: my thesis supervisor, Dr. Patrick Parfrey, for his academic guidance, support and interest in my endeavour to pursue research interests in the nephrology area; Dr. Thomas Hutchinson and Dr. Brendan Barrett for their encouragement and guidance; Dr. Christine Way for her constant guidance, availability and patience. Dr. Way provided me with one-on-one supervision (i.e., interviewing, constant-comparative method of analysis, etc.) during the qualitative phase of the project which lasted approximately 15 months. In addition, she was responsible for training the research assistants in the interview process. Her relentless obsession to explore the "true meaning" of living with ESRD and hemodialysis inspired me to look beyond the concrete and obvious, to the more abstract, subjective experiences of hemodialysis patients.

I wish to express a sincere thank you to a number of other individuals who played equally important, albeit different roles in seeing this project's completion.

To my nursing colleagues of the hemodialysis unit of the Health Sciences

Centre for their support and cooperation during this research project. A special thank you to Cheryl Harding, Nurse Manager, Division of Nephrology, who made initial contact with the patients during the recruitment phase.

To the Allied Health Council of The Kidney Foundation of Canada for providing a Graduate Student Scholarship.

To the School of Graduate Studies for financial assistance during my program.

To Ms. Karen Webber and Dr. Fred Winsor for the invaluable assistance provided during data analysis.

To the research assistants involved with the larger project: Lorraine Murphy during the interview process and Lisa Keeping for her assistance with participant's interpretive summaries.

To Leona Lake for her secretarial assistance during transcription of the interviews.

To my parents, Bernard and Eileen Farrell, who monitored my progress throughout and worried constantly about my workload at home and during my program, your love and encouragement meant so much to me .

To our family's "surrogate mom": Joan Tucker, words cannot express the sincere gratitude for all you have done over the years.

A special thank you to my children Anne, Keegan, Harry, and Peter, for making incalculable sacrifices, understanding the need for long and frequent

absences from your lives, providing encouragement and strength, and countless hugs and kisses during the time I was "going to school". I could not have accomplished this without your love, support and understanding.

To my best friend and confidante, Gabriel Gregory, your love and understanding, constant availability, profound common sense approach to everything in life, tireless efforts to keep me focused on my goals, and belief in me, have been an immense contribution to my success.

TABLE OF CONTENTS

	Page
Dedication	ii
Preface	iii
Abstract	iv
Acknowledgements	vi
List of tables and figures	xii
List of appendices	xiii
Chapter I: Introduction1
Background and Rationale	5
Problem Statement	10
Research Questions	11
Chapter II: Literature Review12
Chronic Illness: Impact of Illness on Self-meanings and Supports . . .	13
Self-Meanings	13
Self-Meanings and Supports	18
Summary21
Adjusting to ESRD and Hemodialysis	22
Stressors and Coping/Adjustment	22
Stressors, Coping and Social Supports.29

Summary	34
Patient Outcomes: Indicators of Quality of Care	36
Patient Perceptions of Quality	37
Satisfaction with Care (General)	39
Satisfaction with Care (ESRD)	43
Summary	45
Discussion	46
Chapter III: Methodology	48
Research Design	48
Sample	51
Procedure	52
Interview Schedule	54
Data Analysis	55
Reliability and Validity	57
Ethical Considerations	59
Chapter IV: Presentation of Findings	61
Characteristics of the Sample	61
Living with ESRD and Hemodialysis	65
Redefinition of Self	65
Emotional/psychological health	66
Adapting to new normal	69

Quality of Supports	74
Informal Supports	75
Formal Supports	79
Meanings of Illness and Treatment	84
Appraisal of Illness	85
Appraisal of Treatment	88
Ambivalence: knowing versus doing	89
Interrelationships Among Theoretical Constructs	92
Discussion	101
Chapter V: Discussion of the Findings	104
Living with ESRD and Hemodialysis	104
Redefinition of Self	105
Quality of Supports	107
Meanings of Illness and Treatment	111
Interrelationships among Constructs	113
Summary	114
Chapter VI: Limitations, Recommendations and Conclusions	116
Limitations of the Study	116
Recommendations for Future Research	117
Conclusions	120
Reference List	123

List of Tables and Figures

Table		Page
1	Characteristics of Participants	62
2	Illness-related Characteristics of Participants	63
Figure 1	The Proposed Interrelationships Among the Theoretical Constructs and the Critical Turning Points	94

List of Appendices

Appendix	Page
A: Consent Form	134
B: Personal Data Retrieval Questionnaire	138
C: Interview Schedule	140
D: Letter of Approval from Human Investigation Committee	144
E: Letter of Approval from the Health Care Corporation	146
F: Tables of Major Categories, Properties and Descriptors	148

CHAPTER I

Introduction

Chronic illness can profoundly affect every aspect of a person's life including physiological, psychosocial, spiritual, and emotional spheres. End stage renal disease (ESRD) is a chronic illness that is very debilitating, while unique in available treatment options. The disease process begins with a normal glomerular filtration rate at the onset of kidney failure, followed by a steady decline in the ability to filter toxins and fluid from the body. ESRD occurs when the kidneys become permanently impaired and cease to function at sufficient levels to maintain life (Canadian Institute for Health Information (CIHI), Annual Report, 1997).

The deterioration of renal function can be abrupt or insidious, and may occur at any age due to a variety of disease processes. In Canada, diabetes (26.8%), glomerulonephritis (15.9%), and renal vascular disease including hypertension (18.1%) are the leading causes of ESRD. Other causes include polycystic kidney disease, pyelonephritis and cases with unknown etiology (CIHI, Annual Report, 1997).

The medical treatment for terminal stages of the disease is renal replacement therapy, renal transplantation or dialysis. According to Canadian statistics for 1995, the average age for commencing ESRD therapy was 57 years, males dominated all age groups, and the number of individuals receiving

dialysis (n = 9,797) exceeded those with a functioning kidney transplant (n = 8,340). In Newfoundland, 210 patients were receiving dialysis versus 222 with a functioning kidney transplant. With regards to the two types of dialysis, hemodialysis and peritoneal dialysis, hemodialysis was the most common form of treatment in Canada (65.3%) and in Newfoundland (55.2%) (CIHI, Annual Report, 1997).

The cost of providing end stage renal disease treatment has escalated into billions of dollars worldwide, resulting in a closer scrutiny of quality of care delivery. The traditional quality assurance model of structure, process, and outcome developed by Donabedian (1980, 1988a, 1988b) guided the development of quality assurance programs over the last two decades. However, emerging models advocate focusing on patient perceptions as opposed to provider perceptions of health care quality (Larrabee, 1996).

For persons living with a chronic illness (e.g., ESRD) quality of care is a continuously evolving concept. In the past, quality of care in hemodialysis units was measured in terms of survival and morbidity, and whether treatment targets were met (e.g., Kt/V, hemoglobin, etc.). With the increased awareness of the important role played by personal experience in shaping perceptions of quality, meanings of ESRD and hemodialysis treatment for patients must be understood if health care providers are to act as facilitators in promoting satisfaction with care and quality care outcomes. It is also conceivable that improved

communications between patients and health care providers during hemodialysis might improve survival. It is important to move beyond the narrow perspective of mortality and morbidity as outcomes of ESRD treatment and focus greater research efforts on subjective experiences with a chronic illness. By generating a data base on illness experiences, health care providers will be able to more effectively monitor illness and disease processes, to identify and develop more timely and appropriate interventions for enhancing both the length and quality of survival, and, most importantly, to provide the health care that meet patients' needs.

The classic paradigm for assessing quality of care views the patient as a more or less inactive recipient of care. The response is assumed to be mechanical (linear) - a direct and easily predictable response to input. This applies whether the outcome assessed is morbidity, mortality, quality of life or satisfaction with care. However, patients are not inactive recipients of care. Their reaction is not necessarily a linear response to the stimulus that caused it. This thesis evolved from a larger research study that focused on the exploration of patients' experiences with hemodialysis, with a goal of developing an interactive model to complement the linear model that currently exists in the hemodialysis environment. In a linear model the primary transfer is energy and the underlying assumption is linear. It was proposed that an interactive model (i.e., where the primary transfer is information and the underlying assumption is

non-linear) would consist of four elements. First, patients are not passive recipients of care. Secondly, patients react to various aspects of their care. Thirdly, it is the patient's reaction to the care that he or she receives that create or destroy the value he or she experiences from treatment. Finally, to increase the value that patients experience from hemodialysis care, health care providers need to develop a greater awareness and understanding of these reactions (i.e., the interactive response to the patient's reaction).

Without a conducive mechanism for listening to patients desires and wishes, it is difficult to assess and direct how health care providers can assure that patients experience value from hemodialysis treatment. An interactive paradigm allows the inclusion of the patient's experience in the assessment and improvement of the quality of hemodialysis care. Therefore, an interactive model, as opposed to a linear one, may be more conducive for promoting high quality of care outcomes with hemodialysis patients. It can be argued that critical events, defined as interactive experiences, create a deep and lasting impression and may have either positive or negative implications for hemodialysis patients.

The service industry is well aware of this phenomenon (Albrecht & Zemke, 1990). The airline industry, as it developed, found that other issues completely separate from the technical issues in delivering the main service (how the engines of the airplane are made and maintained) can have an overriding effect on the consumer's experience of value. These issues are things like punctuality,

helpfulness of the agent, comfort of the environment, the food served, etc. When one or more of these things goes badly wrong, the consumer's experience of satisfaction or value may be destroyed. On the other hand, service above and beyond the call of duty may make a huge difference to value experienced. The stance of the service industries is that the consumer is always right.

Background and Rationale

Hemodialysis is a procedure that involves pumping the patient's blood through an extracorporeal dialyzer. Blood is filtered across a semi-permeable membrane and through the processes of diffusion and convection toxins, electrolytes, and fluids are removed (CIHI, Annual Report, 1997). Hemodialysis is administered to persons with acute or chronic renal failure. This procedure is most often performed by health care professionals in out-patient clinics or hospital settings, and involves patient attendance for 4 - 7 hours, usually 3 times per week. In a small number of cases patients and family members receive training to perform this procedure at home.

In the United States the high rate of morbidity and mortality of ESRD patients has been attributed to hypoalbuminemia, anemia, and inadequate dialysis (Rodriguez, 1997). Hypotension has also been associated with a higher rate of mortality among dialysis patients (US Renal Data System 1992: Annual Report IV; Lowrie & Lew, 1990). Additional predictors of outcome include: (a)

age (Foley & Parfrey, 1997; Harnett, Foley, Kent, Barre, & Parfrey, 1995; Foley, Parfrey, Harnett, Kent, Murray, & Barre, 1996a; Parfrey, Foley, Harnett, Kent, Murray, & Barre et al., 1996a; Parfrey, Foley, Harnett, Kent, Murray, & Barre et al., 1996b), (b) nutritional status (Acchiardo, Moore & La Tour, 1983; Foley, Parfrey, Hefferton, Singh, Simms, Barrett, 1994; Iseki, Kawazoe, & Fukiyama, 1993; Owen, Lew, Yan Liu et al., 1993), (b) immune status (Mattern, Hak, Lamanna, & Teasley, 1982), and, (c) psychosocial factors such as family supports, compliance, and social and demographic characteristics (Burton, Kline, Lindsay, & Heidenheim, 1988; Christensen, Wiebe, Smith, & Turner, 1994; Kimmel, Peterson, Weihs, Simmens, Boyle, Umana, Kovac, Alleyne, Cruz, & Veis, 1996; O' Brien, 1990; Reiss, Gonzalez, & Kramer, 1986). Co-morbid conditions such as diabetes (Foley, Parfrey, Harnett, Kent, Martin, Murray, & Barre, 1995), heart disease (US Renal Data System 1992: Annual Report IV; Foley & Parfrey, 1997; Harnett et al., 1995; Foley et al., 1996a; Parfrey et al., 1996a), and hypertension (Charra, Calemard, Ruffet, Terrat, Vanel, & Laurent, 1992; Fernandez, Carbonell, Mazzuchi, & Petruccelli, 1992; Foley et al., 1996a; Ritz & Koch, 1993), quality of life and adequacy of dialysis (Gotch & Sargent, 1985; Lowrie, 1994; Lowrie, Laid, Parker, & Sargent, 1981) have also been associated with increased morbidity and mortality.

Abram (1977) noted that "chronic dialysis serves as a paradigm not only of man's response to a chronic illness, but to a treatment which requires

dependence upon an artificial device for survival" (p. 307). The long term survival of patients receiving dialysis for the treatment of ESRD is not solely dependent upon the dialysis procedure itself but rather is intricately linked with acceptance of and adjustment to treatment regimens (i.e., medications) and healthy lifestyle behaviours (i.e., fluid and dietary restrictions, activities of daily living). According to the 1995 Canadian statistics, social factors (i.e., primarily withdrawal from treatment) accounted for 13.6% of deaths from ESRD (CIHI, Annual Report, 1997). It has been postulated by others that patients' experiences may also be a predictor of survival (Reuben, Rubenstein, Hirsch, & Hays, 1992).

Despite technological advances in treatment modalities for ESRD, patients receiving hemodialysis are faced with physiological and psychosocial stressors arising from restrictive lifestyles, treatment regimens and the negative impact of living with an uncertain future (i.e., transplant, alternative dialysis options such as peritoneal dialysis, death). Investigations of patients' experiences with hemodialysis have evolved from clinicians' examinations and observations to quantitative measurement of psychological and physiological stressors, methods of coping, quality of life, quality of care, and satisfaction with care.

A number of researchers have focused their efforts on identifying physiological and psychological stressors, and coping strategies used to manage

stressors (Baldree, Murphy & Powers, 1982; Bihl, Ferrans & Powers, 1988; Eichel, 1986; Fuchs & Scriber, 1988; Gurklis & Menke, 1995; Hoothay, DeStefano, Leary, & Foley-Hartel, 1990; Lok, 1996). Studies on hemodialysis patients' satisfaction with care (Ferrans, Powers & Kasch, 1987; Hoothay, DeStefano, Leary, & Foley-Hartel, 1990), quality of life (Ferrans & Powers, 1993; Hays, Kallich, Mapes, Coons, & Carter, 1994; Kutner, 1994; Laupacis, Muirhead, Keowan, & Wong, 1992; Lok, 1996; Parfrey, Vavasour, Bullock, Harnett, & Gault, 1989; Parkerson, Broadhead, & Tse, 1993; Ware & Sherbourne, 1992), or coping and adjustment efforts (Blake & Courts, 1996; Hoothay et al., 1990; Lok, 1996) have used a variety of instruments and samples depending upon researcher preferences.

Other investigators have used a variety of qualitative research methodologies to study different aspects of patients' experiences with renal replacement therapy (Charmaz, 1983; Flaherty & O'Brien, 1992; Hilton & Starzomski, 1994; Kutner, 1987; Molzahn, 1991; Rittman, Northsea, Hausauer, Green, & Swanson, 1993). Holman (1993) discussed the merits of using quantitative and qualitative methods of inquiry by the discipline of clinical epidemiology. Several authors have argued that quality care will never be achieved unless a research data base is developed on patients' perceptions of the total health care experience (Elwood, 1988; Meyer, 1995). However, only a limited number of studies were identified from the literature that addressed the

total patient experience with ESRD and hemodialysis treatment.

The growing recognition of the importance of patients' perceptions of quality of care as an outcome parameter has sparked greater interest in using qualitative methodologies to generate a data base in this area (Fosbinder, 1994; Larrabee, 1996; Pontin & Webb, 1996; Vuori, 1991; Wilde et al., 1993). Other qualitative studies have focused on the meaning of illness in various situational contexts (Kleinman, 1988; Kutner, 1987; Morse & Johnson, 1991), and the interaction of illness meanings and the struggle to regain a sense of normalcy (Charmaz, 1987; Conrad, 1990; Corbin & Strauss, 1987; Fife, 1994; Morse & Johnson, 1991; Robinson, 1993).

Meyer (1995) noted that despite the controversy surrounding the use of subjective experiences as outcome parameters for ESRD therapy, clinicians must give due consideration to experiences which may impact or forecast survival. Meyer also argued that it is possible to measure patient experiences in a reliable and valid manner. The resulting data base could be used for case-mix adjustment, to facilitate greater understanding of choices regarding treatment, to measure quality of care, and, ultimately, to improve the quality of care received by individuals. A number of authors concur with this position (Ellwood, 1988; Lohr & Schroeder, 1990; Tarlov, Ware, Greenfield, Nelson, Perrin, & Zubkoff, 1989; Vuori, 1987, 1991).

Problem Statement

The meanings patients assign to ESRD and hemodialysis have not been investigated to any great extent. Health care providers must try to capture the significance of patients' experiences and find ways of monitoring, evaluating and improving the quality of care delivered and the quality of outcomes.

Some authors (e.g., Burrows-Hudson, 1995; Charmaz, 1987; Conrad, 1990) define the health-illness trajectory as extending for days, months or years for some individuals experiencing a chronic illness such as ESRD. For patients receiving hemodialysis for the treatment of ESRD the trajectory begins with the initial signs and symptoms of kidney disease. Eventually a diagnosis is made followed by a period of renal insufficiency which may last days, months, years, or decades, potential transplantation, the stable and unstable periods such as hospitalization, exacerbation of co-morbid illness states, the effects of the illness and its treatment, and death. It is obvious that critical events can occur anywhere along the illness trajectory and should be evaluated for their impact on short and long-term outcomes. Further, changes in illness and treatment meanings that occur in response to situational and environmental factors are important factors to consider if health care providers are to provide optimal care at each phase of this chronic illness trajectory.

The purpose of the current study was to explore patients' experiences with and perceptions of ESRD and hemodialysis treatment. A second purpose was

to document the significance of critical events associated with hemodialysis treatment for patient satisfaction with care, and to their relative value as compared to the more medical or technical aspects of care.

Research Questions

This study was designed to address the following research questions:

- (1) What is the meaning of the illness/treatment experience for patients on hemodialysis?
- (2) Can common themes be identified from the experiences of hemodialysis patients regardless of age, gender and time spent in hemodialysis care?
- (3) What impact, if any, do "critical events" have on patient perceptions of care quality or satisfaction with care?
- (4) When do "critical events" occur in the hemodialysis cycle, i.e., beginning or end of treatment, early or late in the treatment cycle?

CHAPTER II

Literature Review

There has been a growing awareness over the past two decades that focusing on physiological aspects of an illness to the exclusion of the total illness experience - behavioural, social, psychological and emotional aspects - is a rather limited view of what it means "to live with a chronic illness". The meanings of illness experiences is an empty construct without the understanding provided by individual perceptions of illness in different situational and sociocultural contexts (Charmaz, 1983, 1987; Conrad, 1990; Fife, 1994; Kleinman, 1988; Kutner, 1987; Morse & Johnson, 1991). When the focus is confined to the disease process, the emphasis is on symptoms' manifestations and treatment. However, when the total illness experience is considered, the focus shifts to personal experiences with illness symptoms and the disability consequential to the disease process (Kleinman, 1988).

A review of relevant literature is divided into three sections. The first section presents an overview of studies dealing with the impact of an illness on self-meanings and supports in different groups of chronically ill individuals. The second section summarizes study findings on how individuals adjust to end-stage renal disease (ESRD) and hemodialysis. Special consideration is given to dominant physiological/psychosocial stressors and coping strategies used to deal with them, and the influence of social supports on emotional/ psychological

adjustment. The final section discusses key findings on how quality of care may have a positive impact on the quality of patient outcomes.

Chronic Illness: Impact of Illness on Self-meanings and Supports

How illness and treatment are experienced by the individual and others should not be seen as something static, but rather as evolving over time in response to changing circumstances. Meanings are multi-dimensional, highly volatile and intimately linked with relationships (Kleinman, 1988). The understandings and interpretations of an illness are determined and shaped by the nature of the illness (acute versus chronic, severity and degree of suffering, lifestyle restrictions and extent of disability), by the situational context (work, social and family disruptions), the person experiencing the illness (self-concepts, self-actualization), and the phase of the illness trajectory (Charmaz, 1987).

Self-Meanings

Corbin and Strauss (1984) proposed that the course of a chronic illness progresses along a trajectory with readily identifiable phases. The chronic illness trajectory was conceptualized as individual specific and following a course marked by periods of stability and instability. Corbin and Strauss (1987) conducted interviews with 60 couples, and published autobiographies and biographies to create a meaning context for chronic illness and test their

proposed model. The biographical body conceptions (BBC) chain was coined to capture the interrelationships among three components, biographical time, body failure and conceptions of self, which give structure and continuity to a biography. According to these authors, the cumulative impact of a chronic illness on each component of the BBC chain is dictated by the severity and progression of the illness and its meaning for the self (i.e., changes in body conceptions that guide action-performance adjustments and biographical projections to accommodate illness-related tasks and time management of other tasks). When the BBC chain is shattered, the person must engage in biographical work to reconstruct it and forge new meanings for self-identity. Corbin and Strauss described the integration of an illness-trajectory into a person's biography as a contextualizing process that is never complete, highly subject to variable illness states, and influenced by the self and others commitment to performing tasks that will foster a new self-identity. By coming to terms with the unpredictability of the chronic illness and moving to let-go of the past, the individual searches for new meaning in future possibilities, rearranges priorities, and chooses a biographical scheme that promotes and sustains the self.

Charmaz (1983) interviewed chronically ill individuals ($N = 57$) with debilitating diseases including cardiac disease, diabetes, cancer, kidney disease, and multiple sclerosis. Over two-thirds of the respondents were women between 40 - 60 years of age. Using a grounded theory methodology during data

collection and analysis, Charmaz identified "loss of self" as the dominant theme emerging from the data. The findings suggested that when one's world is dominated by an illness (i.e., excessive lifestyle restrictions, and physical debility), the new self is visualized as a person with a chronic illness (i.e., a male dialysis patient perceived himself as a "captive of the machine"). Charmaz highlighted the importance of the magnitude and frequency of discrediting encounters with others in determining the full impact of the illness upon the self. Charmaz suggested that the perceived magnitude of the discrediting becomes more pronounced when the ill person either feels forced to accept the discrediting denotations and/or perceives them as a stimulus that can further weaken the self. Although the chronically ill persons' views about themselves and ways of being in the world are powerful forces in self-redefinition, the value placed on others' perceptions have equal import.

Charmaz (1987) used a grounded theory methodology to generate a theoretical perspective on how chronically ill individuals ($N = 57$) forged a new self-identity. The findings suggested that the chronically ill are constantly searching for a match between an evolving self (i.e., the here and now) and preferred identities (i.e., future self goals, motivations to achieve them, etc.). There is a constant struggle to construct preferred identities that will facilitate a sense of normalcy and reduce the social stigma of the illness. This construction is depicted as a linear progression up or down an identity hierarchy that is

comprised of preferred identities: the supernormal identity - extraordinary efforts to achieve a desired self while managing an intrusive, serious illness; restored self - expectation that all levels of the old self will be reinstated; contingent personal identity - realignment of future goals following failure to achieve a supernormal or restored self; and salvaged self - the self is perceived in a positive light despite reduced functioning abilities. Movement up and down can be sudden or insidious and permanent or volatile depending on the type, frequency, timing, and severity of illness episodes; the meaning of illness experiences; self-expectations; and the presence of emotional and physical support from informal and formal networks. Charmaz recommended that more research be conducted to understand the processes involved in the struggle for self-preservation during a chronic illness.

Using a grounded theory approach, Mathieson & Stam (1995) used semi-structured interviews to explore cancer patients' (N = 37) perceived threats to self-identity over the course of their illness. Three major themes were identified from the narratives: signals of identity threat; renegotiating identity; and biographical work resulting from disrupted feelings of fit and renegotiating identity. The authors defined illness narratives as the search for personal identities through story-telling about how treatment regimens were negotiated, how adjustments were made to body changes, or how one made sense of a disrupted life. The findings suggested that identity threats were greatest in the

early stages of a cancer diagnosis when disruptions in daily living were more pronounced (i.e., changes in personal relationships and body cues, exposure to the health care system). Illness narratives were subsequently reshaped to account for self-identity threats or "disrupted feelings of fit" experienced from encounters with others (i.e., the social stigma of a cancer diagnosis, learning how to communicate as equal partners with health care providers). The cumulative effects over time, from initial diagnosis to the recognition that a permanent change had occurred, depicted a circular movement from being taken-up with the illness to its diminished importance during "well states", and then refocusing back on the illness during recurrent episodes and decreased functioning. The researchers concluded that self-narratives are continuously being transformed in response to a illness progression.

Fife (1994) used a qualitative research approach to explore how individuals with cancer ($N = 38$) conceptualized illness meanings. An open coding procedure was applied to the interview transcripts to derive theoretical constructs. Two theoretical constructs emerged - self and contextual meanings. Illness meanings were viewed as central to an individual's ability to assimilate the impact of a critical event, place it in an appropriate context, and adapt to its ensuing illness manifestations. Self meanings were continuously being reshaped in response to illness and treatment circumstances and were reflected by: a) loss of personal control - increasing dependency, enhanced feelings of

uncertainty and vulnerability, and reduced predictability of life (i.e., oscillating between hope/optimism and depression/despair), b) threats to self-esteem or self-worth - positive/negative effects on roles and interpersonal relations, c) changes in body image - alterations in identity and self-worth. Contextual meanings were shaped by appraising critical events and their consequences for life in general (i.e., changed goals, altered relationships). For example, a serious illness was found to exert either a positive or negative impact, within and outside the family setting. Subsequent meanings construction could immobilize or empower the person. The findings are somewhat constrained by forcing participants' meanings of critical events within the theoretical premises of symbolic interactionism, limited consideration of an important contextual base, (i.e., health care and its providers), and the obvious overlap of self and contextual meanings (i.e., the self is being constantly redefined by social contexts).

Self-Meanings and Supports

Morse and Johnson's (1991) *Illness-Constellation Model* is an example of a theoretical perspective on illness experience. The model evolved from a meta-analysis of five research projects (i.e., adjustment after a heart attack, women experiencing a hysterectomy, mothers' and their daughters' abortions, leaving the psychiatric hospital, and husbands and their wives' chemotherapy) which

focused on patients' acute illness experiences and the resulting impact on interactions, roles, and relationships of families and friends. Uncertainty, disruption, striving to regain self, and regaining wellness are presented as four stages of an illness experience. In the uncertainty phase, self-monitoring, symptoms and diagnosing illness severity dominate, and family members become cognizant of altered health states. During the disruption phase the person seeks help or is forced to do so because of a crisis episode which may lead to relinquishing control or becoming dependent on health care providers and family. As the individual moves to make sense of the illness by seeking explanations and trying to predict future outcomes, the stage of striving to regain the self is reached. The individual then moves to self-preservation while significant others try to buffer the impact of the illness. Regaining wellness is achieved when one attains mastery by reinstating former relationships, regaining control of self, and adjusting to illness limitations. Success in this stage is facilitated by support and understanding from significant others. There is a logical progression through the stages of the illness from initial suspicions to bringing closure to the episode.

Kleinman (1988) emphasized the differences between disease and illness, and acute versus chronic illness. Referencing research findings and experiences as a clinician, Kleinman suggested illness meanings are defined by the many social worlds of the person of which the health care setting is only one

component. Similar to Morse & Johnson (1991) and Fife (1994), Kleinman noted the ripple effect that a chronic illness may exert on others in the social network, and the altered sense of self in response to others' views and actions. From the perspective of a chronic illness the person and significant others are in limbo emotionally and interpersonally. There is a preoccupation with regaining a sense of normalcy, while doubting if this will ever transpire because the self is being continuously redefined by the illness. Kleinman argued that greater research efforts are needed to understand how illness meanings are created, the process responsible for their evolution, and the role played by social and psychological reactions in shaping their final form. Kleinman also argued for an explanatory model to capture the many ways in which the person assigns cause to illness, monitors the effects of the chronic illness on the self and those comprising the social networks, reconstructs the past within the context of the present, and shapes and redefines illness meanings.

Robinson (1993) investigated how individuals and families dealt with chronic illness in the context of everyday living. A constant comparative method of analysis was applied to the data collected from 62 interviews with 30 women and 10 men, 31 of whom were managing a chronic illness. The findings suggested that study participants tended to focus on a normalization process in constructing a meaning context for their illness (i.e., a struggle to achieve a sense of normalcy). Significantly there was a greater sense of mastery and

competency as opposed to uncertainty, a tendency to conceal differences and focus on the normal (i.e., covering up and promoting the normal), and letting go of unrealistic expectations while trading-off and substituting activities to maintain control over the image projected to others. Robinson also addressed the impact of this normalization process on health care providers, family, and friends. One important finding was that participants perceived health care providers as trying to obstruct the normalization process (i.e., seeing normalization attempts as denial, not supporting activities that facilitated independence). As a result of the drive for normalcy and the desire to "cover up" weaknesses, family members were also not always aware of the amount of assistance required by the person experiencing a chronic illness.

Summary

Some authors refer to the losses resulting from a chronic illness as a weakening of the self, whereas others perceive them as an opportunity to redefine the self. An extensive review of the literature demonstrated a piecemeal approach taken to the exploration of how the chronically ill experience self-meanings or self-redefinition, and the perceived quality of supports. Although the independent effects of these constructs have been addressed in the literature on chronic illness, there is limited consideration of the interactive effects. Significantly, neither the independent or interactive effects have been

investigated in ESRD patients receiving hemodialysis.

Adjusting to ESRD and Hemodialysis

From a health care providers perspective end-stage means "terminal" and as such life on a dialysis machine is "borrowed time" (Kutner, 1987, p. 41). It has been well documented that long-term maintenance hemodialysis patients are exposed to a multitude of physiological and psychosocial stressors and encounter significant lifestyle restrictions and losses. A review of the literature on the physiological and psychosocial stressors experienced by hemodialysis patients, coping methods used to manage these stressors, quality of life, and the role that supports play in adjusting to ESRD and hemodialysis is presented in this section.

Stressors and Coping/Adjustment

O'Brien (1980) conducted a nine year longitudinal study of ESRD patients (N = 126) receiving maintenance hemodialysis treatment in an out-patient setting. The researcher used quantitative (i.e., a variety of researcher developed and/or standardized scales on social and psychological functioning) and qualitative (unstructured interviews with patients, family, and health care providers, non-participant observations of the sociomedical environment of the hemodialysis setting) methods at different data collection points (i.e., year 1, 3,

and 6) to explore the life "career" of maintenance hemodialysis patients. One of the key findings from this study was the central role played by courage in facilitating day to day survival. Another significant finding was the important role played by supportive others (i.e., family, friends) during the initial stages of dialysis in facilitating coping with and acceptance of restrictive lifestyles and the necessity to depend on technology to sustain life. With time, however, the chronicity of the illness and treatment left some feeling alone and uncertain about the future (i.e., family relations, physical functioning, role restrictions, and life itself). Thus, patients with ESRD and receiving hemodialysis were in a constant struggle to maintain courage in the face of an uncertain future. In some instances there was a greater tendency to relinquish responsibility and control to physicians.

Baldree et al. (1982) designed a descriptive-correlational study to investigate treatment-related stressors and coping strategies in a sample of hemodialysis patients ($N = 35$). The Hemodialysis Stressor Scale (HSS) was used to rate the frequency and severity of physiological and psychological stressors, and the Jalowiec Coping Scale the presence of affective versus problem-oriented coping. The authors reported content validity and test-retest reliability for both instruments. Study findings indicated that fluid restriction, muscle cramps and fatigue, uncertainty about the future and food restrictions, and work interference were the most frequently occurring stressors; and,

problem-oriented coping was used more often than affective-oriented coping. In addition, no significant differences were detected between the ratings of physiological and psychological stressors, or significant correlations found between physiological/ psychological stressors and select demographic characteristics or coping behaviours. Study limitations include a small, non-representative sample (i.e., time on dialysis, age, etc.).

Eichel (1986) investigated stressors and coping methods in a sample of chronic ambulatory peritoneal (CAPD) patients (N = 30). The HSS and the Jalowiec Coping Scale were used during data collection. Study findings from the CAPD group were compared with those of Baldree et al. (1982) findings from hemodialysis patients. Although the CAPD patients reported less overall stress than hemodialysis patients, similarities were noted in identified sources of stress (e.g., fatigue, limitation of physical activity, muscle cramps, changes in body appearance, itching and work interference). Another point of contrast between the two groups was the higher ratings given to physiological over psychosocial stressors by the CAPD group. Comparatively, problem-oriented coping was used more often than affective-oriented coping by both groups. However, the CAPD group used affective-oriented coping strategies significantly less often than the hemodialysis group. Trying to maintain control, looking at the problem objectively, prayer, accepting the situation, hoping things will get better, and thinking through and trying different solutions were common to the top 10 for

both groups.

Bihl, Ferrans, and Powers (1988) examined stressors, quality of life, and health status in a sample of CAPD ($n = 18$) and hemodialysis ($n = 18$) patients. Study variables were assessed by a modified version of the HSS (i.e., altered three items relating to hemodialysis patients only, and added items to assess dialysis equipment, treatment-related discomfort, and boredom with the routine), the Quality of Life Index, health status on a 10-point rating scale, and biophysical markers (e.g., serum potassium, weight, creatinine, etc.). The researchers found that uncertainty about the future and restrictions on leisure time were the highest ranked stressors for the CAPD group, whereas fatigue and boredom were the highest ranked stressors for the hemodialysis group. In contrast to Eichel (1986), Bihl et al. (1988) found no significant differences between CAPD and hemodialysis patients overall ratings' of physiological and psychosocial stressors. A noteworthy limitation of this study is the small sample size.

Fuchs and Schreiber (1988) compared CAPD ($n = 30$) and hemodialysis ($n = 30$) patients perceptions of stressors. The researcher developed instrument, the Stressor Assessment Scale (Chronbach's $\alpha = 0.84$), was based on the HSS of Baldree et al. (1982) and Luby's (1984) scale. The findings indicated that hemodialysis patients ranked limited physical activity, limited time or place for vacation, and fluid limitation as most stressful; whereas, CAPD patients ranked fatigue, limited physical activity, and sleep disturbances as being

most stressful. There were no significant differences noted between CAPD and hemodialysis patients in the number and intensity of stressors. These findings concur with those of Bihi et al. (1988).

Gurklis & Menke (1988) replicated Baldree's (1982) study with a sample of hemodialysis patients ($N = 68$). In contrast to Baldree et al. (1982), these researchers found a significant difference between patients ratings of physiological and psychosocial stressors. Although similar high ratings were found for fatigue, and fluid and food restrictions, subjects did not rate uncertainty and muscle cramps as highly as in the Baldree et al. (1982) study and gave significantly higher ratings to physical activity limitations and frequent hospitalizations. Although comparable findings were found for the dominant coping strategy (i.e., problem-oriented coping) in both studies, in contrast to Baldree et al. (1982), Gurklis and Menke (1988) found a significant correlation between coping methods and stressors. Gurklis and Menke (1988) suggested that differences in the findings between the two studies could be attributed to the older patient population and longer time on hemodialysis in their study. Further, the researchers noted content validity problems with the HSS, identifying an additional 30 treatment-related stressors (e.g., hypotension, unwell feeling states after dialysis, clotting of the fistula, etc.).

In a later research effort, Gurklis & Menke (1995) used a triangulated study design to explore hemodialysis patients ($N = 129$) perceptions of stressors,

coping methods, and social support. From the interview data, 62 stressors were identified and categorized as physiological and psychosocial stressors, concerns about starting hemodialysis, restrictions of living with a chronic illness, and kidney transplant concerns. Approximately 54% of the subjects experienced one or more physiological stressors (e.g., fatigue, hypotension, feeling unwell after dialysis, cramps, nausea and vomiting, decreased mobility, bone pain, too much fluid removal). Psychosocial stressors were defined in terms of missed activities, having to come in for dialysis, time consuming activity because of the travel, time sitting in a chair to receive treatment, and the time involved resting at home recovering from treatment. Patients defined the restrictions of living with chronic illness in terms of difficulties encountered in maintaining a normal life due to physical symptoms, unexpected hospitalizations, the stress of dealing with diet and fluid restrictions and lifestyle changes, and financial constraints. Forty-eight coping strategies were collapsed into six major categories and reported as acceptance, optimism, maintaining control, seeking support, self-mastery, and staying active. The coping methods used in this study were comparable to those methods reported in other studies (Baldree et al., 1982; Eichel, 1986; Gurklis & Menke, 1988; Hoothay et al., 1990; O'Brien, 1990).

Lok (1996) used a descriptive/correlational study design to compare the relationship between stressors, coping methods and quality of life among hemodialysis and CAPD patients ($N = 64$) in two dialysis centres. The HSS, the

Jalowiec Coping Scale, and a quality of life index were used during data collection. The results indicated that limitation of physical activity was the highest rated stressor among all patients. Other stressors identified by the hemodialysis group included decreased social life, uncertainty about the future, fatigue and muscle cramps. Among CAPD patients sleep disturbances, length of treatment, stiffening of the joints, and uncertainty about the future were the highest ranked stressors. The top stressors identified in this study sample were comparable to findings of Baldree et al. (1982) and Gurklis & Menke, (1988), however, the rank ordering differed. Similar to Baldree et al.'s (1982) and Gurklis & Menke's (1988) findings, Lok (1996) found problem-oriented methods of coping used more often than affective-oriented methods. In contrast to Gurklis and Menke's findings, length of time on dialysis was not significantly associated with method of coping. Patients' perceptions about their physical activity, social activity, and satisfaction with life was below average in both dialysis groups. In terms of the relationship between stressors, coping methods and quality of life, problem-oriented method of coping was the only factor significantly associated with total stressors in hemodialysis patients. Study limitations included the low number of CAPD patients enrolled ($n = 8$), poor response rate to the questionnaire (58%), and lack of established reliability and validity of the HSS developed by Baldree et al. (1982).

Stressors, Coping and Social Supports

Patients undergoing hemodialysis for ESRD experience a multitude of physiological and psychological stressors. By virtue of the illness chronicity and the consistency with which such stressors occur, patients and their families and friends are consequently exposed to the illness and treatment effects. Several studies have focused on the role that supports play in coping with and adapting to hemodialysis.

Siegal, Calsyn, and Cuddihee (1987) used quantitative and qualitative research methodologies to examine the effects of social support on psychological adaptation to hemodialysis treatment in ESRD patients. The sample ($N = 101$) consisted of 56 males and 45 females. The Brief Symptom Inventory was used to measure psychological adjustment, and a researcher-developed questionnaire measured leisure time activity and frequency of contact with friends, family, physicians, religious organizations, volunteer organizations, and a "confidant". The majority of patients identified their families as the primary source of social support, with health care providers and friends rated second and third, respectively. The findings also depicted a significant, positive correlation between perceived quality of support and degree of psychological adjustment.

Kutner (1987) designed a longitudinal study to investigate the impact of different social worlds on individuals' ($N = 150$) experiences with end-stage renal disease (ESRD). A variety of data sources were used during data collection (i.e.,

semi-structured interviews with and administration of physical/cognitive motor/psychological scales to hemodialysis and peritoneal patients; ESRD patients' anecdotal notes gathered by the National Kidney Foundation of Georgia; an assessment of the ESRD program by the Inspector General's Office; writings and presentations by individuals with ESRD; and the researchers' clinical experiences). The findings suggested that ESRD is a chronic illness that has a major impact on family relations (i.e., accepting and adjusting to the illness, realigning of roles and responsibilities, and being burdened by care), friendships (i.e., aware of restrictions while trying to maintain normal relationships), and maintaining active employment (i.e., nature of job, receptivity of employer). In comparison to other chronic illness ESRD was seen as unique because of the important influence of the social world of dialysis (i.e., perceived social, emotional, and informational support received from dialysis peers and health care providers). Kutner concluded that supports from existing and emerging social worlds significantly influence the ability to rebound from the initial jolt of the diagnosis (i.e., sudden versus insidious onset of kidney failure), to positively deal with ambivalence concerning the quality of life on dialysis, and to effectively manage uncertainty associated with longevity, the risks and benefits of different treatment options and declining health status. The centrality of treatment diminished as the person strived to maintain a sense of normalcy in life and overcome sickness versus wellness and/or independence versus

dependency dilemmas.

In a longitudinal study of hemodialysis patients, O'Brien (1990) used an exploratory correlational design and panel analysis to investigate compliance behaviours and social support. The initial sample was 126, with 63 remaining at the second interview at three years, and 33 remaining at six years. Standardized interviews were used to collect data from family and care givers on social supports, patient compliance behaviour, and sociodemographic characteristics. The findings indicated that patients who died early in the hemodialysis cycle tended to be more compliant with diet and fluid regimens. However, patients who were married and/or living with other adults and children reported higher compliance behaviors. Interestingly, those patients who survived the longest were the least compliant, most satisfied with social interactions with family and friends, and more socially active.

Christensen, Smith, Turner, Holman, Gregory, and Rich (1992) used a descriptive/correlational, longitudinal study design to explore the effects of social support on patient adherence to fluid and dietary compliance and level of physical functioning in a sample of in-center ($n = 55$) and home ($n = 26$) hemodialysis patients. Physical functioning was measured by the Sickness Impact Profile, social support by the Family Environmental Scale, and physical status by interdialytic weight and serum potassium levels. The findings indicated that adherence to fluid restrictions varied by treatment modality (i.e., greater

adherence for in-center hemodialysis vs home hemodialysis patients) and level of family support (i.e., higher support, greater adherence). In addition, adherence to dietary restrictions varied by treatment modality (i.e., greater adherence for in-center hemodialysis vs home hemodialysis patients) and level of physical functioning (i.e., higher physical impairment, lower adherence).

In a subsequent article, Christensen, Wiebe, Smith, and Turner (1994) reported on the ongoing analysis of data from the earlier study by Christensen et al. (1992). Christensen et al. (1994) investigated the effects of select demographic and clinical variables (i.e., age, sex, time on dialysis, diabetic status, depression, social support, and serum creatinine, urea nitrogen, phosphate and potassium), on survival in a sample of 84 hemodialysis patients. Depression was measured by Beck's Depression Inventory. During the regression analysis only age, urea nitrogen, and family support surfaced as significant predictors of survival. Significantly, study findings suggested a three-fold increase in the risk of death for patients with low support compared to those receiving high levels of support.

In a descriptive-correlational study, Tell, Schumaker, Mittelmark, Russell, Hylander, and Burkart (1995) investigated dialysis patients ($N = 256$) perceptions of social support and health-related quality of life. Consideration was given to select demographics during sample selection (i.e., gender, race, age, hemodialysis vs home dialysis). Perceived social support was measured by the

Interpersonal Support Evaluation List (Chronbach's alpha of ≥ 0.73), and actual social support the Lubben Social Network Scale (Chronbach's alpha = 0.70). Health-related quality of life was assessed by rating two items on life experiences (i.e., feelings about life as a whole, life satisfaction), the Karnofsky Scale on Physical functioning, and verbal reports of activity limitations. The findings indicated that Blacks rated overall quality of life and life satisfaction higher than Whites, reported better physical functioning (i.e., based on patients and nurses ratings), and identified less restrictions on leisure activities. However, no significant differences were noted between Blacks and Whites in terms of perceived or actual supports. When social support variables were correlated with the quality of life indicators, only perceived support depicted a significant, positive relationship with physical functioning.

Flaherty and O'Brien (1992) used an exploratory/descriptive, longitudinal design to investigate styles of coping in family members ($N = 50$) of ESRD patients on in-center hemodialysis, home dialysis, CAPD, or Continuous Cyclic Peritoneal Dialysis. The Family-Focused Interview Guide was used to conduct open-ended interviews with family members. Five major styles of coping were identified during data analysis (i.e., remote family style, enfolded family style, altered family style, distressed family style, receptive family style). What was most revealing about the study findings was the emotional and physical distancing from the significant changes experienced by the affected family

member (i.e., remote family style) consequential to ESRD and its treatment. One possible explanation for this finding was the early stage of treatment and the absence of co-morbid conditions. Another limitation of the study was the small sample with diverse characteristics (i.e., age, race, gender).

Gurklis & Menke (1995) examined and described stress, coping, and social support among 129 hemodialysis patients using a combination of qualitative (i.e., open-ended questions) and quantitative (i.e., Hemodialysis Stressor Scale, Jalowiec Coping Scale, Personal Resource Questionnaire) methods of research. Over 90% of the subjects perceived one or more immediate family members as providing support. Spouses or significant others were identified by 46.5% of the patients followed by adult children (44.2%). The majority of patients (89%) expressed positive feelings about the perceived quality of support by relatives and friends. Overall, 31% of the patients attributed the fact they were still alive to the support provided by family, friends, health care providers, and home care services particularly during serious illness episodes.

Summary

Many research studies (Baldree, Murphy & Powers, 1982; Bihl, Ferrans & Powers, 1988; Blake & Courts, 1996; Eichel, 1986; Gurklis & Menke, 1995; Hoothay, DeStefano, Leary, & Foley-Hartel, 1990; Lok, 1996; O'Brien, 1980) provided useful insights into dialysis patients treatment concerns, dominant

coping strategies, and possible ways to manage concerns and enhance coping abilities. However, the literature reviewed on stressors and coping strategies revealed inconsistencies in study findings (Baldree, Murphy & Powers, 1981; Bihl, Ferrans & Powers, 1988; Gurklis & Menke, 1995; Lok, 1996). This is an area that requires further investigation with larger samples of dialysis patients. Further, methodological limitations must be addressed in future studies (i.e., longitudinal designs, content relevant and psychometrically sound instruments, etc).

The association of family support and patient adherence to treatment regimens and death has also not been well researched in ESRD and particularly hemodialysis. It is conceivable that the perceived quality of supports (i.e., family, friends, volunteer organizations, etc.) can influence health behaviours (i.e., adherence to diet, fluid, and medication regimens) directly through concrete support or indirectly by altering the patient's psychological approach to health behaviours (i.e., promoting a positive approach to management of the illness and its treatment regimens). This is a relatively new concept which requires longitudinal study of not only patients but family members. This type of research data base is needed to help gain a deeper understanding of the role perceived quality of informal supports play in facilitating adherence to medical treatment and survival.

Patient Outcomes: Indicators of Quality of Care

Donabedian (1980,1988a,1988b) defined quality as the ability to achieve set objectives in different situational contexts. From this theoretical perspective, judgments about quality of care vary depending on the indicators measuring health outcomes (i.e., physiological versus quality of life) and other influencing factors (i.e., organizational structure of the care environment, and the technical and interpersonal processes involved in giving and receiving care). This traditional quality assurance model of structure, process, and outcome has stimulated work on the strategic position held by patient outcomes (e.g., Greeneich, 1993; Jirsch, 1994; Peters, 1995; Sawatzky & MacDonald, 1994; Woodyard & Sheetz, 1993).

Traditionally, the adequacy of hemodialysis treatment was primarily evaluated in terms of technical achievement (process) and mortality (outcome) (Barth, 1993; Bergstrom, 1985; Burrows-Hudson, 1995; Lowrie, Laird, Parker, & Sargent, 1981). Several authors have argued that focusing on the technical aspects of care is a fragmented approach that ignores the whole person (Capelli, 1994; Larrabee, 1996; Peters, 1991). A more interactive approach to measuring quality of care is supported by an increasing number of theorists and researchers. Peters (1991) defined quality within interactive driven systems as opportunity because patients become active participants in the care process and instrumental in shaping the quality of outcomes.

Patient Perceptions of Quality

Patients' perceptions of interactions with the health care system are significantly shaped by their experiences, the evolving meanings of illness and treatment, and the perceived quality of supports. Jirsch (1993) suggested that an exploration of patients subjective experiences is needed because future quality health care initiatives will be defined by patients' perceptions. Koch (1994) argued that disregard for patients' experiences within the health care system results from a preoccupation with the scientific method, and heavy reliance on input from health care providers to determine the parameters for quality care delivery. Despite the increased emphasis placed on patients' perceptions for assessing quality of care by Continuous Quality Improvement (CQI) and Total Quality Management (TQM) initiatives, there continues to be a fairly high degree of incongruency between consumers and health care providers perceptions of quality care (Larrabee, 1995; Meyer, 1995; Pettit & White, 1991; Vuori, 1991).

Young, Minnick and Marcantoni's (1996) conducted a stratified random survey of patients ($n = 2051$), nursing staff ($n = 1264$) and nurse managers ($n = 97$) from hospitals ($N = 17$) with a reported CQI or TQM program in the Midwestern region of the United States. The purpose of the survey was to compare patients, nurses, and nurse managers perceptions of the importance of selected aspects of care. In addition, patients were asked to rate the

effectiveness of actual services provided, and nurses and nurse managers the degree to which they desired to meet patients expectations. Study findings identified considerable gaps between patient and nurses priority ratings and expectations regarding physical care, patient participation in care, and patient teaching and pain control. The researchers concluded that health care providers must achieve a greater understanding of patients' priorities for care and needs and wants, and use this information when delivering care. A major limitation of the study was the absence of any reference to the reliability and validity of survey instruments.

There is also a growing qualitative research base on the value patients place on interpersonal competencies of health care providers, and how this component of quality may promote positive health outcomes. In an ethnographic study of patients perceptions of nursing care, Fosbinder (1994) applied the constant-comparison method of analysis to the data generated from observations of nurse-patient interactions ($n = 145$) and patient interviews ($n = 75$). The findings highlighted the priority ratings that patients give to the interpersonal skills of nurses, especially in the areas of information sharing, getting to know patients, establishing trust, and being friendly and doing the extras.

Wilde, Starrin, Larsson and Larsson (1993) used a grounded theory methodology to examine patients' ($n = 20$) perceptions of quality of care received

at an outpatient clinic. Study findings suggested that perceptions of quality care result from interactions between patient preferences (i.e., rational and human aspects of care) and the resource structure of the care environment (i.e., person, physical and administrative qualities). Four dimensions of quality of care were identified: medical-technical competence of caregivers (i.e., desire to be treated by knowledgeable and technically competent caregivers), physical-technical environmental conditions (i.e., a safe, clean, and comfortable environment), identity-oriented approach (i.e., caring and accepting approach, participatory dialogue), and sociocultural atmosphere (i.e., attention to patient needs/desires, positively charged atmosphere). The model emphasizes that patients desire to be cared for in a humane way by qualified care givers with technical and interpersonal competences and skills. Similar theoretical insights on the importance of the interpersonal, intellectual, and technical competencies of nurse caregivers were made by Taylor (1995).

Satisfaction with Care (General)

Health care institutions, recognizing the importance of monitoring quality of care, tended to rely on patient satisfaction as an indicator of quality (Marr & Greengarten, 1995). Much of the work on patients' perceptions of quality care has focused on satisfaction with care. Hall and Dorman's (1988a, 1988b) meta-analysis of quantitative studies (N = 211) measuring patient satisfaction with

medical care found significant conceptual and methodological limitations (e.g., use of non-standardized instruments which varied on directness, specificity, type of care and dimensionality) that created problems for interpreting and comparing study findings. In a concurrent meta-analysis of 41 studies on predictors of patient satisfaction, Hall, Roter, and Katz (1988) investigated the consistency of study findings on the impact of provider behaviours. These authors reported that patient satisfaction seemed to depict a significant and consistent correlation with provider behaviours (i.e., greater technical and interpersonal competence, more efforts at communication and partnership building, greater amount of information giving, etc.) (Hall et al., 1988). In addition, Hall et al. (1988) found that patients who reported a higher degree of satisfaction with health care tended to be more compliant with treatment regimes.

Pontin and Webb (1996), in an ethnographic study of hospitalized surgical patients ($N = 40$), combined open-ended interviews with observational techniques to explore satisfaction with care. Study findings suggested that nurses observation and monitoring of physical, psychological and emotional states influenced patient satisfaction with nursing care; and, physical conditions (e.g., cleanliness, decor, physical space, and privacy) and resources (e.g., adequacy of staff and meals) influenced overall satisfaction with the hospital stay. Similar to Hall and Dorman's (1988a) meta-analysis findings, Pontin and Webb (1996) found that patients' criticisms of care were expressed in a "socially

accepted" manner. For example, workload demands or financial cutbacks were used to rationalize perceived differences between the quality of care expected and received.

Rempusheski, Chamberlain, Picard, Ruzanski, & Collier (1988) used a retrospective exploratory/descriptive design to investigate patients' and families' perceptions of nursing care expected and received during hospitalization. A modified grounded theory method was applied to a random selection ($n = 63$) of 239 letters received from patients/families over a three-year period. Four major theoretical constructs were identified from the data base - elements of care required to make a judgment about quality (i.e., patient/nurse characteristics, service quality, etc.), patient/family judgment of care (i.e., critical junctures/ events influencing nurse-patient interactions and satisfaction with care received), options for action (i.e., perceived alternate care sources based on patient/family judgments about care expected/received or not received), and outcomes or lasting impressions of care (i.e., overall satisfaction with nursing care). Based on preliminary theoretical insights, Rempusheski et al. (1988) concluded that critical nursing events play a significant role in shaping patient and family satisfactions with nursing care.

Comparatively, Greeneich's (1993) theoretical model on patient satisfaction also highlighted the important mediating role played by critical nursing events. The proposed model depicts the interaction of the nurse,

patient, and organizational environment along a "critical juncture continuum". Critical events may result in a general level of dissatisfaction with care that may be maintained for an indefinite period of time. Although the author stressed the importance of using qualitative data to generate inductively derived theories to guide instrument development for monitoring patient satisfaction, the proposed model was derived from conceptualizations based on a review of research findings reported in the literature.

With an increasing emphasis placed on expanding patient outcomes (i.e., functional status, general well-being and satisfaction with care) and the effects of organizational structure and technical and interpersonal processes, one group of researchers launched an extensive program to address these issues. Tarlov, Ware, Greenfield, Nelson, Perrin, and Zubkoff (1989) designed a two-year observational study to investigate the impact of systems of care (e.g., prepaid group practice form of Health Maintenance Organization, clinician specialty, or physician's interpersonal and technical style) on variations in patient outcomes. Perceptions of health outcomes and satisfaction with care were examined in a sample of patients ($N = 2349$) diagnosed with hypertension, diabetes, depression and coronary heart disease. One important offshoot of this project was the establishment of a Medical Outcomes Trust to facilitate development of reliable and valid instruments to measure patients' perceptions of health and health care outcomes (Paget & Tarlov, 1996).

Satisfaction with Care (ESRD)

It has been argued that the degree of success of any ESRD quality assurance program is measured by such outcomes as quality of life, mortality, morbidity, access, and patient satisfaction with care (Levinsky & Mesler, 1994). However, a comprehensive review of the literature on patient satisfaction with ESRD in general and hemodialysis in particular demonstrated a lack of research conducted in this specific area.

Elliwood (1988) defined outcomes management as "a technology of patient experience designed to help patients, payers, and providers make rational medical care-related choices based on better insight into the effect of these choices on the patient's life" (p. 1551). Kurtin (1995) recommended using report cards to quantify outcomes and indicators of outcomes (e.g., patient satisfaction) in order to substantiate claims of providing high quality care, whereas, Van Valkenberg and Snyder (1994) suggested that resources be earmarked for areas showing the greatest potential for achieving patient-based outcomes (e.g., patient satisfaction, quality of life, and rehabilitation).

Other researchers have noted that patient satisfaction with care, interpersonal competence, provider characteristics, among others, remain unexplored areas in ESRD research (Meyer, 1995). Although controversy surrounds the inclusion of total patient experiences as an outcome measurement, its importance has been emphasized by several researchers

(Ellwood, 1988; Lohr & Schroeder, 1990; Meyer, 1995; Paget & Tarlov, 1996; Tarlov et al., 1989). A conducive mechanism for listening to patients subjective experiences would facilitate the identification of the aspects of care that may enhance or destroy patients' experiences with ESRD.

Some researchers have used a combination of quantitative and qualitative approaches to investigate satisfaction with care in hemodialysis patients (Ferrans, Powers, & Kasch, 1987; Gurklis & Menke, 1995). Ferrans et al. (1987) used a descriptive-correlational design to explore the relationships among satisfaction with care, quality of life, and background variables in a randomly selected sample of hemodialysis patients ($n = 416$). The Satisfaction with Care Questionnaire was used to measure satisfaction with physician and nursing care, dialysis treatment, and financial and transportation implications. Quality of life issues (i.e., health and functioning, socioeconomic, psychological/ spiritual, and family) were measured by the Quality of life Index. The researchers reported that both instruments had good reliability and validity. Study findings indicated that patients were quite satisfied with health care overall. In addition, the total satisfaction with care score depicted a significant, positive correlation with the total quality of life score and each subscale score; and education and time on dialysis surfaced as significant predictors of overall satisfaction with care.

Fukunishi (1993) explored satisfaction with hemodialysis therapy and desire for transplantation among a sample ($N = 275$) of Japanese hemodialysis

patients. Psychological problems of kidney transplantation were examined in aged (i.e., ≥ 60 years) and non-aged (i.e., ≤ 59 years) groups. Although study results demonstrated a high degree of satisfaction in both groups, complaints were noted regarding constraints on time, economics, etc. The study was limited by the fact that patients who were on dialysis less than two years were excluded from the study. Further, it is unclear how culture influenced the responses to the questionnaire.

Summary

Quality of care delivery in ESRD programs has been guided for the most part by outcome measures such as mortality, morbidity, and adequacy of treatment. Other indicators of quality care such as patient satisfaction with ESRD programs have received limited attention. The growing recognition of the limited usefulness of focusing on the technical aspects of care as opposed to the influence of the effects of the illness and treatment on the whole person has sparked greater interest in finding ways to monitor and improve quality of care.

In order to provide optimal quality care and promote quality outcomes, it is imperative to know and, more importantly, understand patients' perceptions of treatment effectiveness and the extent to which care has been delivered in an effective and efficacious manner. Further, it has been argued that, in order to achieve quality outcomes, organizations must ensure adequate physical and

human resources, reduce the gap between provider and patient expectations and values, and invest in both the technical and interpersonal skills of front-line workers (Bauman, 1991; Bliersbach, 1988; Cleary & McNeil, 1988; Donabedian, 1988a, 1988b; Greeneich, 1993; Jirsch, 1993; Larrabee, 1995; Marr & Greengarten, 1995; Meyer, 1995; Paget & Tarlov, 1996; Peters, 1991, 1995; Tarlov, Ware, Greenfield, Nelson, Perrin, & Zubkoff, 1989; Taylor, 1995; Williams, 1994; Young, Minnick & Marcantonio, 1996).

Discussion

The review of the literature identified key factors which influence adjustment to ESRD and hemodialysis treatment (i.e., meanings of illness and treatment, formal and informal social networks and sources of support, loss of self and struggling to find a new self). However, there is limited understanding about their independent and interactive effects on the quality of outcomes. Greater attention must be given to the meanings of patient experiences at all levels of interaction, internal and external to the health care system, in order to grasp the significance that personal and situational factors play in shaping quality outcomes.

Methodological variations and study limitations (design, content validity and psychometric validity of instruments) may have contributed to the inconsistent findings found in the literature review of the relationship between

stressors, coping, quality of life, and supports. Concern has been raised about the reliability and validity of some of the instruments used to measure these key variables affecting ESRD patients. The small sample sizes coupled with the inclusion of patients on hemodialysis and CAPD in a number of studies reviewed reduce the significance of the findings. Based on study findings these two patient populations seem to differ in their experiences with stressors, use of coping methods, quality of life, and perceived quality of supports.

Quality of care is a continuously evolving concept for persons living with chronic illness. Further, quality does not always translate into positive outcomes for the chronically ill. To date researchers have not presented a clear picture of what it really means to live with ESRD and hemodialysis treatment. In order to capture the meanings ascribed to illness and treatment it has become vital to explore all factors which shape ESRD and hemodialysis treatment meanings. How a person experiences interactions with the health care system is significantly shaped by the evolving meaning of illness and treatment and the pervasiveness of self redefinition. Although illness severity and the effectiveness of technical support are important factors influencing outcomes, the literature also suggests that adjustment to illness chronicity, the presence of supportive significant others, acceptance of treatment regimes, and the tension between desired and expected and the actual treatment outcomes exert a powerful impact on the quality of outcomes.

CHAPTER III

Methodology

A qualitative research design using a grounded theory approach was used to explore patients' experiences with ESRD and hemodialysis treatment and to identify the meanings and significance of critical events for patient satisfaction with care. The constant comparative method of analysis was used to discover and describe conceptual categories present in the data. As potential relationships between the major theoretical constructs were tested within the data, a substantive theory began to emerge. This chapter provides an overview of the research design, sample, interview schedule, procedure, data analysis, and ethical considerations.

Research Design

Grounded theory is an inductive process which may be used to generate either a substantive or formal theory. This research approach was developed by sociologists Glaser and Strauss (1967) and later refined by Glaser (1978, 1992), Chenitz and Swanson (1986), and Strauss and Corbin (1990) to facilitate greater understanding of human behaviour and interactions. Glaser and Strauss (1967) defined a substantive theory as that developed for a substantive, or empirical area of sociological inquiry. Examples of a substantive theory include patient care and race relations.

Formal theory is developed for a formal, or conceptual, area of sociological inquiry. Examples of a formal theory include stigma, deviant behavior, formal organization, and socialization. Sociologists and anthropologists have used the constant comparative method of analysis to generate substantive theory in areas with limited research, as well as in well-researched areas, in order to shed new light on key constructs/variables.

A minimal review of the literature focusing on patient satisfaction with hemodialysis was conducted at the beginning of the research process. To avoid making pre-judgments, a more in depth literature review was done after data analysis was completed to define selected concepts (i.e., emerging categories guided the subsequent search for relevant studies), identify previously published studies focusing on the emerging concepts, and fill in gaps in the emerging theory.

Grounded theory involves the simultaneous collection and analysis of data. Theoretical sampling is the dominant method used during data collection. This form of sampling involves the deliberate selection of study participants based on their knowledge of the area of interest and the needs of the emerging theory (Morse & Field, 1996). Thus, the ongoing thematic analysis influences the type of questions/probes used with study participants.

Glaser and Strauss (1967) used the term categories to describe groups of events or situations with similar attributes. The characteristics of a

category are termed properties, whereas incidents from the data that are used to define category properties are labelled descriptors. During data analysis all pieces of data are compared with other relevant data from the transcripts, field notes or tape recordings. All transcripts are analysed line by line and open codes, based on participants own words, inserted into relevant margins. This form of coding helps reduce researcher bias. The codes are assigned to similar or dissimilar themes, ideas, thoughts and/or perceptions. Subsequently, common concepts described by respondents are allotted descriptive labels.

In the second stage of analysis, the researcher collapses the open codes, without altering the identified concepts, into key properties which are aligned with emerging categories. The generation of descriptors (i.e., grouping and collapsing of indicators/incidents from the data), properties and categories are constantly reassessed for validity and reliability. As the descriptors and properties defining each category approach a saturation point theoretical sampling ceases. Eventually, as properties and categories are further refined, interrelationships between the categories are proposed and a clear delineation of the major constructs and relevant linkages become apparent.

Sample

The target population ($N = 70$) was all patients receiving hemodialysis at a university teaching hospital in St. John's, Newfoundland. Forty-four potential subjects for the study met the following eligibility criteria: on hemodialysis for a minimum of 12 weeks; mentally competent - able to understand the interview process and study purpose, and give informed consent to participate in the proposed research; fluent in the English language; 19 years of age and over; and not experiencing an acute illness episode (e.g., acute renal failure and under critical care services) and/or significant decline in health status (e.g., terminal phase of dialysis, psychological maladjustment). Of the 44 eligible patients 36 (81.7%) agreed to participate. The reasons varied for refusal but the researcher was not provided with this information.

Although qualitative research generally requires much smaller sample sizes (Morse, 1996), higher numbers were initially projected for this study for a number of reasons. First, it was important to identify when critical events were most likely to occur for patients during the hemodialysis cycle. Because of the limited knowledge on how critical events may affect perceptions of care quality or satisfaction with care, it was necessary to recruit participants at different time periods in the hemodialysis cycle (i.e., less than one year, one to three years, three years or longer). Second, it is possible that socio-

demographic variables (e.g., age, gender, social supports) may also impact satisfaction with hemodialysis therapy. If any of these variables were found to exert a significant influence on perceptions, then greater sample numbers would have been needed to account for the observed variations. Third, a long-term objective of the larger study was to develop a reliable and valid instrument to assess patients' perceptions of their experiences with ESRD and hemodialysis treatment. In order to meet this objective, sufficient data were needed to generate representative items for empirical testing.

Procedure

Potential participants were identified through consultation with the Nurse Manager of the Division of Nephrology at the Health Sciences Centre. Patients were approached by the nurse manager during a scheduled appointment to briefly explain the study and ascertain their willingness to be approached by a member of the research team for a more in-depth overview of the study. Those who indicated an initial willingness to participate were contacted while receiving hemodialysis. The study was explained more fully at that time, and a copy of the informed consent (see Appendix A) given to potential participants to reflect upon between scheduled treatments. Subsequent contact was made to address any questions or concerns, and schedule an interview at a time and place that was convenient for

participants. Informed, written consent was obtained prior to the beginning of each interview.

Data collection was undertaken between April and September 1996. A personal data retrieval questionnaire (see Appendix B) was completed on each participant. Socio-demographic and illness-related data were also obtained during the interview. Semi-structured interviews, averaging 60 to 90 minutes, were audio taped with participants' permission, and conducted in a private place chosen by the participant (e.g., room adjacent to the dialysis unit, at home or researcher's office). The interviews were recorded to facilitate conversational flow and accurately capture the responses of participants. Personal logs on perceptions, observations and analytical thoughts were kept by the research assistants following each interview.

Three participants were interviewed in their homes, four a private office, and the remaining twenty-nine in a private room adjacent to the central dialysis unit, during their hemodialysis treatment. The dialysis unit was the most common setting chosen by the participants largely due to the perceived convenience of combining the interview with the scheduled treatment. Participants were interviewed following initiation of hemodialysis, generally in the first hour and a half. Interviews were temporarily halted, from time to time, to allow for routine monitoring by health care providers.

Given the importance of the interview process in eliciting a rich data

base in qualitative inquiries, training sessions were conducted with the research assistants prior to data collection. These training sessions were conducted by the principal investigator of the larger study who has an extensive theoretical and experiential base in qualitative research. The training sessions emphasized the importance of being attentive to what was being conveyed by the verbal reports, probing for clarifications of participants' meanings, and being sensitive to emotional responses that indicated discomfort and/or difficulty with certain topics. In order to reinforce the basic premises of the training sessions, the principal investigator also participated in the first 3 to 4 interviews conducted with study participants.

A second interview was scheduled 6 to 8 weeks following the initial interview to confirm interpretive summaries constructed from each participant's transcript. Participants were also asked questions on identified gaps in the data, and to confirm conceptual categories and properties. The second interviews were much shorter, approximately 20 minutes, and were not audio taped. Each participant was offered a copy of his/her interpretive summary.

Interview Schedule

The interview schedule developed for this study was designed to explore key aspects of study participants' experiences with ESRD and

hemodialysis treatment (see Appendix C). Open-ended questions were based on relevant literature, insights and understandings gathered from clinical experiences of physicians and nurses, and themes generated during the interviews and ongoing data analysis. Question content was designed to generate data on the total illness trajectory (e.g., emotional, physiological, and psychological reactions to illness, treatment and critical events; perceived quality of informal and formal supports).

As data collection and analysis progressed, additional probes and questions were incorporated to test and refine emerging categories, to extract further information from the participants, or to seek clarification on issues discussed. It is important to note that because data collection and analysis occur simultaneously in qualitative inquiries, it was impossible to anticipate all possible questions/probes ahead of time. Further, some participants were better informants than others (e.g., ability to recall and relate experiences). Thus, there were variations in terms of the numbers of probes and/or questions required for any particular interview.

Data Analysis

The constant-comparison method was used during data collection and analysis (Glaser & Strauss, 1967). Taped interviews were transcribed verbatim within 48 hours and checked for accuracy by research assistants.

During data transcription listening to the participants tape recorded interviews enhanced the researchers' understanding of the total experience of living with ESRD and hemodialysis treatment.

Following transcription of the interviews and accuracy checks, the constant-comparative method of analysis was applied to the first 15 data sets by two raters/coders working independently. The first stage of analysis focused on interpreting the meaning of words and sentences through reading and re-reading each transcript. This involved identifying indicators for words, phrases or sentences, and assigning codes to recurrent themes. A meaning context was then sought by forging determinate relationships between and among codes. This generated a multi-layered classification system of major categories and associated properties, descriptors and indicators. This period was followed by ongoing debriefing sessions to clarify themes and emerging conceptual categories. This concentrated time with the data was intensive, resulting in multiple revisions of the initial categories and their properties and thematic descriptors (eight drafts). The coding team eventually agreed upon 3 conceptual categories with variant numbers of properties and indicators.

Although a sample size of 40 to 50 was projected, theoretical sampling indicated that common themes were emerging from the ongoing data analysis of the first 15 to 20 transcripts. Category saturation (i.e., no new data emerging) was achieved following analysis of 30 data sets. At this point

in the analysis, the theoretical model (i.e., theoretical constructs and linkages between them) was beginning to emerge from the data. However, the team wanted to ensure that all of those who had indicated a willingness to participate were given an opportunity to share their views. Data collection was stopped after thirty-six interviews to finalize conceptual categories and properties.

Reliability and Validity

Reliability and validity are not generally addressed in grounded theory. Rather, reviewers of qualitative research tend to focus on the credibility of the study. However, researchers have identified the need for evaluative methods to enhance the rigor of qualitative research (Hinds, Scandrett-Hibden & McAulay, 1990). In the current study, three steps were taken to enhance the reliability and validity of findings.

First, the credibility and accuracy of the classification system was facilitated by subjecting it to examination by independent consultants experienced in using the constant-comparative method of analysis. This resulted in collapsing properties and categories into a more parsimonious set (i.e., 10 to 7 categories, and 48 to 36 properties) and to descriptor labels being added to differentiate meaningful divisions within properties. The revised classification system was further refined by the research team before

proceeding with recoding of the data. The raters/coders worked to ensure that the categories, their properties and descriptors were exhaustive and had minimal overlap.

Second, the data suggested that "critical events" could potentially exert a powerful and long-term impact on the value patients' place on hemodialysis treatment. Critical events were defined as experiences that created a deep and lasting impression, and may instigate a "turning point" by altering the patient's entire attitude towards his/her treatment. Because many of these critical events surfaced as descriptors defining the properties comprising different conceptual categories, each transcript was subsequently perused to single out those events that appeared to be crucial to the integrity of independent categories. Reliability and validity were assured by having two researchers construct independent interpretive summaries of each transcript and achieve consensus on the final version. Participants were then given an opportunity to read, or receive a verbal presentation on their interpretive summaries. The focus of this stage of analysis was not only to receive confirmation on the accuracy of conceptual categories and their properties, but also determine the weight and importance attached to critical events by study participants. All participants' confirmed their interpretive summaries, adding a further element of credibility to the findings.

Third, the initial 20 data sets were recoded with the revised

classification system. Difficulties with overlapping categories continued to impede the coding process. It became readily apparent that certain categories had comparable meanings but from slightly different perspectives. Further discussions between the independent consulting team and the research team collapsed the categories from 7 to 3 and the properties from 36 to 18. In the final phase of analysis all data sets were recoded with the revised classification system, and an interrater agreement of 95% achieved.

Ethical Considerations

Approval to conduct the proposed study was requested and granted by the Human Investigation Committee, Memorial University of Newfoundland (see Appendix D) and the Research Proposal Approval Committee of the Health Care Corporation of St. John's (see Appendix E). All potential participants were given an explanation of the study purpose and voluntary nature of their participation. Informed, written consent was obtained immediately prior to commencing the interview. Appropriate measures were taken to ensure that confidentiality of all data was maintained. All tapes and transcriptions were coded, and kept in a secure place. A log of names and matching codes was stored in a locked filing cabinet, accessible only to the research assistants and principal investigator. Researchers who were part of the participants treatment team did not have access to taped interviews,

transcripts or any other information that could potentially identify the patient as the source. Participants were also informed that all information collected would be described in a manner that would prevent identification of the source, no direct benefits were anticipated, and they were free to withdraw from the study at any time. This study had no identifiable negative consequences for those willing to participate.

CHAPTER IV

Presentation of Findings

Study findings are presented in three sections. The first section presents a brief overview on key demographic and illness-related characteristics of the study sample. The second section describes the theoretical constructs (i.e., redefining the self, quality of supports and the meanings of illness and treatment) that were generated from an analysis of participants' transcripts. The final section discusses the interrelationship between the constructs and proposes a model to depict the total patient experience of living with ESRD and hemodialysis. When forced to separate out the various themes describing the total experience, one somehow violates the complex and rich context of individual experiences.

Characteristics of the Sample

This section presents a descriptive profile of study participants. The target population ($N = 70$) was all patients receiving hemodialysis treatment at a university teaching hospital in St. John's, Newfoundland. Of the 44 eligible patients 36 (81.7%) agreed to participate. The study sample was equally divided by gender, with the majority married (69.4%). The mean age was 57 years, with a range of 19 to 87 years. Table 1 summarizes selected sample characteristics.

Table 1**Characteristics of Participants (N = 36)**

Characteristic	n	%
Gender		
Male	18	50.0
Female	18	50.0
Age in Years (M = 57.08; SD = 18.21)		
< 35	6	16.7
35 - 49	4	11.1
50 - 65	15	41.6
> 65	11	30.6
Marital Status		
Single	6	16.7
Married	25	69.4
Separated	1	2.8
Widowed	4	11.1
Employment Status		
Employed	2	5.6
Unemployed	3	8.3
Retired	19	52.8
Ceased work due to illness/treatment effects	12	33.3
Financial Concerns		
none	25	69.4
minor	1	2.8
major	10	27.8

Table 2**Illness-related Characteristics (N = 36)**

Characteristic	n	%
Primary Renal Diagnosis		
Glomerulonephritis/Autoimmune Diseases	13	36.1
Polycystic Kidney Disease	2	5.6
Diabetes	7	19.4
Congenital/Hereditary Renal Disease	2	5.6
Renal Vascular Disease	3	8.3
Other	9	25.0
Length of Time on Dialysis (M = 2.66; SD = 3.24)		
< 1 year	15	41.7
1 - 3 years	11	30.5
> 3 years	10	27.8
Number of Comorbid Illnesses		
0	5	13.9
1	12	33.3
2	11	30.6
3	3	8.3
≥4	5	13.9

The primary causes of renal failure were glomerulonephritis/autoimmune diseases (36.1%), diabetes (19.4%), and other conditions (25%). Compared to Canadian Institute for Health Information (CIHI) 1995 statistics the study group had a higher percentage of patients with glomerulonephritis/autoimmune diseases as a primary cause of renal failure (i.e., 36.1% versus 15.9%) and a lower percentage of diabetics (i.e., 19.4% versus 26.8%). The majority of participants (52.8%) in the current study reported two or more comorbid conditions including diabetes. Significantly, the CIHI 1997 report indicated that the presence of 2 or more comorbid conditions (e.g., hypertension, cardiovascular disease but excluding diabetes) decreases survival time for all renal replacement treatments combined. As of December 31, 1997 nine of the thirty -six participants had died, five with two or more comorbid illness excluding diabetes.

Most subjects were either retired or had ceased working prior to dialysis due to a chronic illness (86.1%), and lived with a supporting adult (88.8%). The average length of time on dialysis was 2.66 years, ranging from 3 months to 12.25 years. Travel time to the dialysis unit ranged from 4 minutes to 5 hours ($M = 43.3$ minutes), with 66.7% of subjects travelling 15 to 20 minutes. The average time for each dialysis was 3.65 hours, ranging from 2.5 to 4.5 hours, and the majority required treatment 3 times per week (80.6%). A descriptive summary of illness-related variables is presented in Table 2.

Living with ESRD and Hemodialysis

The interview transcripts provided a rich data base on participants' experiences with ESRD and hemodialysis treatment. This section presents a detailed discussion on the dominant theoretical constructs (redefinition of self, quality of supports, and the evolving meaning of illness and treatment) generated from the thematic analysis of study data.

Redefinition of Self

As participants' were confronted with the uncertainties and dilemmas of illness and treatment experiences, they struggled to adjust to an emerging "new normal". Understanding and accepting potential benefits from engaging in health-seeking behaviours (i.e., lifestyle modification and seeking medical treatment) are not always easy to appreciate when one is experiencing unpredictable illness episodes of varying acuity. The ups and downs of a chronic illness pose threats to the physical, emotional, psychological, and social selves.

The redefinition of self category emerged from participants' descriptions of emotional and psychological functioning in response to variable health states and the personal adjustments made to facilitate acceptance of this new sense of self. Adapting to a new normal consisted of the emotional/ psychological adjustment to illness chronicity, the routine and effects of treatment, and lifestyle restrictions. While adapting to a new normal, the majority of participants

assumed the burden of decision making (i.e., accepted body readiness/chose among treatment options, implemented control measures, assumed responsibility for self-care, weighed the odds). The key properties and descriptors included in the redefinition of self category are presented in Appendix F.

Emotional/psychological health. The data suggest that most participants were not prepared for the significant changes associated with commencing hemodialysis. This was true whether they saw themselves as being in good health, or experiencing an acute illness episode or chronic illness. The early weeks and months were marked by periods of emotional upheaval and lingering doubts about the future as participants strived to achieve a new sense of self while on a journey plagued with uncertainty and emotional struggles and dilemmas.

Some participants referred to a "loss of self". The sadness and despair which resulted from a perceived loss associated with a remembered old self and the emergence of a new self was expressed in the following statement by a young woman struggling to achieve some balance in her life: "I don't feel that I'm the same person I was two years ago. I mean that person is gone." This participant's negative image of self-worth was captured in such descriptives as feeling helpless, dependent, humiliated, and demoralized.

The experience of losing control over kidney function and becoming

dependent on the dialysis machine undermined the sense of security about the self. While notable improvements in health and well-being became a positive force facilitating acceptance, declining physical health and reduced benefits from dialysis posed significant barriers. One man described his struggles adjusting to a new self: "I mean I got no strength in me like I used to It's in my mind that I would like to do something but I can't hold up to it So it's an awful challenge, it sure is." Another man talked about the difficulties accepting reduced benefits from treatment and adjusting to a significant decline in physical health: "I can't walk any distance The last year or so it's worse Oh, them first years, like I said, number one, I didn't mind it a bit." A number of women articulated similar emotional difficulties in trying to adjust to diminished activity tolerance. One woman commented on the numerous losses and changes: "Now I have to stay home all the time My neighbour lives just in the road I can't even walk as far as her place, you know. It does change your life." For these participants, it became an emotional struggle to maintain a positive sense of self in the face of significant physical losses.

Others were challenged to find a "goodness-of-fit" between the "old self" and the emerging "new self". A number of participants' clearly articulated how they had constructed a meaningful context for the reduced lifestyle imposed by illness and treatment events. One man described how he was adjusting to physical limitations imposed by the illness and treatment:

And I guess to an extent I still feel great. But I am not able to do the things that I used to do . . . I'll tire out quicker now . . . But I mean if I pace myself I can go all day.

This man was able to conquer anxieties and lingering doubts by deriving satisfaction from the things that he could still do. Another middle-aged, self-employed man also recognized and instituted necessary changes.

I had to move my mind off an individual who was high energy and had no health problems, to one who was high energy with some health problems. . . . I didn't have that drive I've always had all my life. . . . And I wasn't able to carry out those things that made me what I am.

Several participants talked about the emotional struggles/dilemmas involved in trying to maintain a positive attitude towards the illness, accepting treatment restrictions and coming to terms with the illness, and dealing with the uncertainty of treatment effects on health and quality of life. Maintaining a positive attitude was a commonly identified coping mechanism. One middle-aged woman described the important role that a positive attitude played in facilitating adjustment and a sense of normalcy:

But I don't let it, you know. Like I don't stay awake at night worrying that tomorrow I have to come in for dialysis. And I didn't stay home from my vacations because I had to go on the dialysis machine, right . . . I try to have a good attitude about it.

One patient experiencing positive effects from dialysis explained why he had no difficulty accepting this form of treatment: "There is nothing you can do . . . I know its going to help me . . . Keep me alive. I might as well take the treatment." Some participants viewed dialysis as giving them a new lease on life.

For those who continued to experience improved health, it was much easier to maintain a positive attitude towards dialysis: "If you were sick, dialysis is the most comforting thing that you could ever do."; "And when I come in on dialysis, it does me great. I come off dialysis I feel about ten times better."

The cyclic changes in physical health (i.e., periods of wellness versus deterioration) eventually began to take their toll on the emotional, psychological, social and spiritual aspects of the self. As feelings of ill health came to dominate the lived world, it became more difficult to maintain a positive attitude: "I want to live as long as I can. But when you get that sick, you come to the point that you can't. You know, what is the point?" Although fully aware of the consequences of not receiving treatment (i.e., deterioration of health, eventual death) some participants voiced skepticism about the benefits derived from treatment. This perspective was expressed by a woman who was experiencing deteriorating health and finding dialysis physically and emotionally draining:

I'm sure if I went for a week without dialysis that I would be very sick
But I don't feel that coming three times a week for dialysis has improved my health If anything it has made me a lot worse.

Still others lived in hope of a better tomorrow: "That's all. Waiting and hoping that I'll get a call [*for a transplant*] someday."

Adapting to new normal. Adapting to the new normal was defined in terms of the physical, emotional, psychological and social changes occurring within the person with ESRD. The movement from the remembered "old self" to

the "new self" represented only one side of the coin. The new normal was also undergoing continuous transformation as the person became more or less comfortable with illness chronicity and treatment effects.

As participants began to settle into the role of a person with a chronic illness, some expressed uncertainty about treatment benefits and its implications for their overall quality of life. Participants were also becoming increasingly aware of changes in activity tolerance. One man expressed a diminished ability to do household or work-related activities:

First along it [*dialysis*] didn't bother me in the least. But after I was on for a while I began to feel the effects of the work I did it started to take its toll. I couldn't do the things that I used to do before.

Another man made the following comment: "I don't know how much time I got left. Things are not getting any better. My system is starting to break down."

Besides the alterations in physical health, participants described the emotional/psychological difficulties adjusting to critical events experienced while on dialysis. One woman summed up her experiences with access site, cramping and hypotensive problems, and delays in getting on the machine thus: "You have to learn to have a lot of patience, you know." Another man who experienced ongoing problems with dialysis made this comment: "So you accept it and there's no use complaining and moaning, you know. You just live one day at a time I don't see any other way out."

Although participants were aware of the limited choices with dialysis as

the only available option (i.e., "It's something you know you got to do."), the passage of time did not always alleviate the frustrations of adjusting to the routine and lifestyle restrictions. Participants either learned to accept the routine of dialysis or reject it, found it difficult or easy to relax on dialysis and non-dialysis days, or adjusted to or resisted lifestyle restrictions. One man who had been on dialysis for over ten years identified what frustrated him most:

It's a routine you get into The only thing that bothers me is what I can't do because I'm in here It disrupts my day My lifestyle is really restricted.

Another man who was on dialysis for two years commented on how lifestyle restrictions affected his quality of life: "The biggest change, I would say that anyone would have to make, is in the quality of your life You can make it easy or hard for yourself." One young woman who had been on dialysis for only seven months articulated how easy it could be to give in to the emotional, psychological, and physical demands of the illness and treatment: "Oh, you can give up over there [*dialysis unit*], you can give up real easy. But you got to keep going." However, she did acknowledge that it was best to fight the illness and come to terms with its restrictions.

For some participants adjusting to and accepting the treatment regimen remained elusive. One woman who had been receiving dialysis for about sixteen months described her unrelenting discomfort:

Usually when I go on the machine I'm quite cheerful and talking to the nurses and the patients and within a half an hour I'll start to get upset and

very, very (pause) um, like I can't settle down. Like my legs are moving and my hands are moving and I have to sit there and I have to sit still because I've got two needles stuck into me and I can't be moving around at all.

Another young woman who had been on dialysis for eight months following a 10-year reprieve (i.e., kidney transplant) felt that she might never emotionally/psychologically adjust to the treatment: "I don't think you do adjust to it [*hemodialysis*] really. You're just waiting for the moment that you can leave and not come back anymore, right."

Other participants seemed to be more accepting of treatment demands.

One man who had been on dialysis less than one year while waiting for a kidney transplant expressed comfort with the routine:

They get the needles all set up and I get organized for four hours and I read my *Globe and Mail*. I read my book. I listen to my music. I eat. I have my meal. I chat with everybody. They take me off and out I go and go home. It's just to me, it's a meeting. . . . It's booked, I do it and just go on again.

For others, the passage of time was the only thing that helped them adjust to treatment demands. One man who had been forced to retire because of negative illness and treatment effects indicated how significant lifestyle restrictions, crushed hopes, and diminished quality of life delayed his acceptance of dialysis treatment: "It took me a few years before I got used to it."

In the process of adapting to a new normal, participants strived to retain some sense of control by assuming the burden of decision-making. This component of adapting was reflected in the degree to which the person

implemented control measures, assumed responsibility for self-care, weighed the odds, and chose among treatment options. One man talked about his attempts to maintain some semblance of normalcy in his life: "This might sound funny but I try to let it not control me." Others perceived the need to be vigilant (i.e., monitoring nursing and medical care) and involved in self-care activities. The importance attached to self-care responsibility was reflected in the following comments: "And if I get a nurse who is not that familiar with me, I'll certainly fill them in at the beginning, you know. I feel that I'm doing that to help them as much as me."

Most patients struggled with weighing the odds at some point during their illness trajectory. For example, one young man explained:

I'm trying to put my odds together, what's best for me (pause) to have this transplant or not to have it. I'm afraid I could end up quite sick again and I don't know if mentally I could handle it again.

Others were able to weigh the odds, choose among treatment options, and implement control measures. One woman discussed how she maintained control of her health care by actively participating in treatment decisions:

. . . the girl here in the unit she came and talked to me about home dialysis but I wasn't really interested in it. I had talked about it with my family doctor before and he recommended . . . Hemo because of the situation I was in with my bad heart. So I had it in my mind regardless of what anyone said. I wasn't taking home dialysis . . . I had more of a relaxed mind . . . To come in here . . . Because what are you going to do if you get in trouble at home with your blood pressure or anything else?

As time on hemodialysis passed and exposure to fellow patients

experiencing varying levels of acuity increased, some patients' developed a heightened sense of awareness that declining health and eventual death occurring sooner rather than later was a reality. One woman who had been on dialysis for four years and was experiencing a decline in physical health expressed a desire to provide an advanced directive to those involved in her care: "That's why I said that I don't want to be dialysed when they [*health care providers*] are not making me any more comfortable than some of these patients that have been out there." Another man maintained control by remaining steadfast to his conviction that he would decide, ultimately, whether to continue to receive dialysis or not - he would have "the final say".

Quality of Supports

Quality of supports is a multi-dimensional concept which is constantly being appraised by persons living with ESRD. The person on hemodialysis is continuously being redefined in response to perceived illness manifestations (i.e., improving or worsening health status) and others' reactions to the new self. The quality of supports category emerged from participant descriptions of their experiences with informal (family, friends, fellow patients) and formal supports (nurses, physicians, other health care providers).

From the perspective of family and friends, the person moves from being independent and valued for what s(he) does, to someone with a chronic illness,

who is becoming increasingly dependent upon others. Equally important members of the informal support network are fellow patients. The social world of the dialysis unit is both a source of emotional support and emotional turmoil (i.e., exposure to variable health states, critical events, losses through death). From the perspective of formal supports, changing perceptions about quality of care reflect a movement from initial expectations based on past encounters with the health care system (good or bad, long or short) to current views shaped by variant and similar experiences with different nurses and physicians in the hemodialysis unit.

Informal supports and nursing and medical care effectiveness were the dominant properties defining the quality of supports category. The key properties and descriptors included in this category are presented in Appendix F.

Informal supports. Perceptions about the amount and type of support provided by family, friends and fellow patients, and the impact of the illness and treatment requirements upon others (i.e., spouse, family, friends), and efforts to protect them from the burden of care, emerged as important themes shaping the property of informal support roles. The tremendous value placed on the provision of emotional support and encouragement is captured in the following statements:

Like if he [*husband*] hadn't been there when I was sick I wouldn't have made it He was the fellow that was keeping me going.

I think I'm lucky. I count my blessings. Because I have such a wonderful

family.

The willingness of others to maintain relationships and provide overwhelming caring and interest surfaced as an important force facilitating comfort and acceptance of the illness and treatment. This aspect is reflected in the following statements:

I don't know. She always calms me down. Like if anything happens, just talking to her makes me feel better. Me and mom were always close. She gave me her kidney.

Weil, all the family is there. I'm not left alone and they're coming and going all of the time. And then if they want to go somewhere they want me to go with them. There's really never a dull moment around home that kind of way. It's not like I have to go home and stick in the corner and don't see no one. We have another crowd coming once a week, and we play cards and all this sort of stuff. So, I look forward to that. That breaks up the time.

The majority of participants also described how family and friends assisted with transportation and chores, monitored activities and changing health states, and sought information about and reinforced decisions concerning treatment options. Without assistance from family and friends, many participants would have found it difficult to cope with the demands of daily living (e.g., financial, decision-making, etc.).

Oh, my wife and my children Well they said, 'You have to go in to XX's [dialysis site]. If you want to go in, we'll try to get you back and forth'. . . . So most everyday now there is one of them in with me or one of my buddies they work it out somehow you know.

Like if he [*husband*] sees a lot of fluid on me, he'll say, 'Oh my God', you know, something like that. 'You better watch what you're drinking' or something like that right He doesn't want me to get sick I guess.

He [*husband*] went to the library and got all the information on it [*Goodpastures disease*] He [*husband*] got him [*brother*] to see what he could find out about it and send it down to us. His sister in the States, she sent us a pile of stuff on it We did our own research. He's [*husband*] like that.

Many participants were also concerned about the potential negative impact of their illness on family members (e.g., social and dietary restrictions, exposure to illness episodes, time commitments, care giving role, overprotective attitude, etc.). Adapting to a reduced lifestyle and coping with the magnitude of the illness were viewed as the greatest areas of conflict and concern. One young woman described how her illness compromised her parents lifestyle:

Like they're kind of afraid to do stuff they sold the cabin because they wouldn't go up there. Because they were afraid to leave me here by myself it's kind of limiting their life.

Recognizing the sacrifices of significant others, measures were implemented, when possible, to help reduce the emotional impact and protect them from the burden of caregiving. The following comment illustrates this effort:

Why should I punish them [*family*] for something that I have And I would suggest to anybody on dialysis not to burden their families. You know try to be as independent as you can and to help yourself.

Fellow patients were also identified as an important source of support. Many talked about the "family-like atmosphere" in the dialysis unit and the comfort and support derived from positive interactions with dialysis-peers (i.e., relationship building, informational and emotional support). It was obvious that socializing with fellow patients, the sense of family cohesion and shared

understandings of illness/treatment effects promoted emotional/psychological adjustment to dialysis:

We're all in the same boat I suppose we're one big happy family to a point.

All the patients out there are like one family. Like when you come in one patient worries about the other person.

There was also a down side (i.e., more sensitive to the reduced quality of life, vulnerability to unpredictable treatment events and death) to developing close relations with fellow patients. Many described the emotional impact of being exposed to acute illness episodes of others:

I find it really bad when I see somebody in here who is really sick and suffering. I find that tortures me . . . I have nightmares about this place almost every night.

That's the hardest part I believe though, going over there and looking at the people sick.

Some participants developed an increased level of awareness and appreciation of the dismal reality that they were living on borrowed time. Others talked about how vulnerable they felt following the death of fellow patients.

I mean when someone dies, (pause) when it's an elderly person it's not as bad but when it's someone young and it hits home or that sort of thing, it's around my age group, I do dwell on that. It happened here a couple of weeks ago and actually it's still not out of my mind. A young girl died and it was her first dialysis and it just happened. My life flashed in front of me and it's still on my mind. I can't stop thinking about it for some reason. And I had a friend that was on dialysis, XX. And when she died I thought I died too, that sort of thing.

Then you start thinking about yourself then, how much time you got left, I still think about it.

You feel miserable. Leaves you with a miserable feeling.

Formal supports. Early in the hemodialysis cycle limited knowledge of the dialysis machine and potential problem areas, as well as heightened anxiety levels and emotional adjustment difficulties, impeded clear differentiation between good and poor quality care. Participants viewed the roles of doctors and nurses differently (i.e., satisfaction with physicians was determined by their availability when problems surfaced, whereas, with nurses it was their constant presence and ease of access).

Nursing care effectiveness surfaced as the dominant property in the quality of supports category. Patients' descriptions of dialysis experiences highlighted the importance attached to nurses' technical and interpersonal competence. With regards to technical competence, most indicated that they were comfortable with nurses' skills and clinical judgments and the amount of attention given to individual needs and variable health states.

. . . if they [*nurses*] see a change in you, they know right away. Once they get used to you, they can tell.

Well, you know they [*nurses*] would come over and check me a little bit often, more often And they would introduce themselves . . . very nicely.

Anything goes wrong they [*nurses*] are there to help you. They're right on the ball.

However, some participants indicated that not all encounters with nurses were positive. One woman described her experiences in this manner: "But the

younger girls they're not so good at it [*needling dialysis access site*] because I suppose, they're not experienced." A second woman felt that the nurses did not always respond in a timely manner when she became sick during a dialysis-run: "If you feel sick, or you know, they mightn't be there right when you want them." Another man complained about nurses who performed their duties carelessly: "It's like, I think, it's not watching everything close enough, right."

With respect to interpersonal competence, the supportive and caring approach displayed by nurses was often seen as a major force enhancing comfort, reducing anxiety and uncertainty, and fostering emotional/psychological adjustment to dialysis. Nurses were valued for demonstrating a caring attitude, promoting understanding and acceptance of illness and treatment regimes, accepting a patient as a person and providing comfort measures. One elderly man described nurses supportive and caring manner in the following manner:

And I can assure you that they [*nurses*] care about you as much as anyone could . . . if you got real problems and you are taking a beating like, you know, they do it with a tear in their eye.

A young woman who was appreciative of nurses sensitivity to what she had to endure while on dialysis made the following comment:

I know everybody has to go through a bit of pain. And one of the nurses said to me yesterday, "You're tough aren't you?". . . . And I said 'We got to act tough, if we don't act tough Nothing will keep us up.' And she said, "You got to be tough to be going through what you are going through Those needles alone got to be tough enough.' So they do recognize everything that you are going through, yeah.

Positive comments were also made about nurses receptivity to questions and

willingness to give time and interest to address concerns. An elderly man described nurses approachability thus: "I find if you need to talk, or ask them something, they go out of their way to explain it to you."

Although most participants viewed nurses favourably, some did express dissatisfaction with the caring behaviours and attitudes of a few nurses. One woman made the following observation: "I find that I still need their [*nurses*] attention and their affection, and I'm not getting it." Another man commented on the attitudes displayed by nurses at different times: "It's not because of their [*nurses*] inability either But I just get that uncomfortable feeling."

As well, many patients identified the presence of a nonconducive work environment (e.g., limited and cluttered space) and inadequate staffing levels as significant barriers to the delivery of efficient and effective nursing care. The following comments illustrate how these conditions influenced perceptions of quality nursing care:

I don't think any nurse can walk a straight line I don't think that's efficient. I think for them that's stress. And that can move its way down to the patients perhaps I mean if you got a stressed out staff they can't be 100%. Now maybe they don't need to be 100% to do the job. But there are times that you need to be 100% because if things hit you, you need to be at 100% to react.

But I find that they [*nurses*] haven't been able to do their job the way that they could do it because of the cutbacks and under staffing that does reflect on patient care but I certainly don't blame them for it.

But they don't have the nursing time and care to give to the patients that they should have. And they got everybody's life in their hands as far as I'm concerned I mean my life is in their hands when I am on that

machine And it's not the nurses, I don't blame it on the nurses.

Comments about medical care were also differentiated on the basis of perceived technical and interpersonal competence of nephrologists. For the most part, patients were confident with doctors' skills and clinical judgments and their attentiveness to individual needs and variable health states. One man who had multiple problems with his dialysis access site was quite appreciative that the physicians' were successful in rectifying the problem: "They done some job on it. I never had a bit of trouble with it after." Another man felt confident that the physicians involved with his care had adequately apprised him of his unsuitability for a kidney transplant: "They never gave me any guarantee of a kidney transplant, where I had the heart problem. So there was no disappointment there. They never built up any hope. They just said that I would live a more comfortable life."

Some participants did express dissatisfaction with physicians disregard for their opinions or wishes. One man made the following comment: "And they wanted to put me on Eprex, and nobody talked to me about my hemoglobin. You know, there was just no consultation." A young woman commented on how physicians discounted her assessment of what was wrong with her: "They wouldn't listen to me and I knew it was the kidney. And they kept saying, 'No, it's not the kidney making you sick'."

Other participants voiced concerns about the restricted availability and

rotation schedules of physicians assigned to the dialysis unit:

In my experience, you don't see many doctors Most of them, I must say, they all know their work, they're all good . . . if you can get them to come in to you.

The only thing that I don't like sometimes is this changing [*rotation*] sometimes its not good because they don't know what happened to you last week.

I don't see so much of the doctors. But I find them good. You can talk to them They do rounds about once a week. They come in and ask how you are doing and you say, 'I'm fine.' And they're gone again. . . .if you need the doctor he will come in right away I must say that they have been really good. They are only right around the corner.

Participants differentiated between the perceived effectiveness of physicians' interpersonal skills in terms of whether or not they treated patients as persons or were willing to promote understanding/acceptance of illness and treatment requirements. The following excerpts capture some of these differences:

Some doctors are coming around and talking to you and explaining stuff to you, and more wouldn't give you the time of day.

Who [*doctors*] think you don't know what you are talking about. You're not supposed to question.

[*patient smiles*] Most of the doctors are Ok. There are others that are not Ok There are some that don't have a good bedside manner. But other than that I find them good doctors themselves right. For treating and that. Just their personality I guess Well some of them are more abrupt than others. And others take time with you to explain things more. [*pause*] Sometimes they might be busy or something that they can't get in.

One man identified a defining moment when exposed to a physicians angry

response following his request for information on the disease process and possible care options: "His immediate reaction was one that I was intruding into his area. . . . So he was blustery."

Critical events were also used to define medical care effectiveness. The following illustrates the importance attached to interpersonal aspects of medical care:

I did about a three or four or five page list of my understandings and questions. . . . [Doctor] came walking in at a rapid pace and came right up to me, and got very angry with me. . . . And said, 'Who do I think I am to think that he has the time to sit down and answer all of these questions,' and that sort of thing. And I found that a defining moment of his view of how things ought to be done. He backed off I wanted to see the slides analyzing my biopsy. . . . And so he did take two or three hours to go over it with me. So it was ok.

Meanings of Illness and Treatment

The complex array of indicators reported by study participants captured movement along an illness trajectory from initial diagnosis through current treatment and health status to consideration of future possibilities and outcomes. Understandings and interpretations of encounters with ESRD and hemodialysis were shaped by situational (i.e., past experiences, knowledge) and socio-cultural factors (cultural background, values, beliefs), lifestyle changes, and critical turning points (improved health, illness episodes, losses). Actions and behaviours reflected variant understandings about the illness and the importance of treatment regimens; knowledge did not always translate into consistent

behaviours.

Cognitive appraisal of illness, cognitive appraisal of treatment and ambivalence (knowing prescribed regimens and why they are needed versus adhering/complying to the regimens) were dominant themes in the meanings of illness and treatment category. A summary of the important properties and descriptors is presented in Appendix F.

Appraisal of illness. Participants conveyed variable awareness and understanding of predisposing illness factors and their severity. Whether informed about ESRD following an acute illness episode or lengthy chronic illness, the information was often unexpected and for many difficult to understand or accept. One woman who lost complete functioning of both kidneys after a short illness conveyed her understanding of precipitating causal factors in this manner: "That's [*Goodpasture's disease*] what killed the kidneys. I know a bit about it now because I did a lot of research on it, right. At first I didn't know if it was fit to eat." In contrast, a man with a history of chronic hypertension and progressive kidney disease was also unprepared for the diagnosis of ESRD: "Oh, I had high blood pressure for 10 or 12 years. . . . I didn't realize it [*damage to kidneys*] at all until I got on the machine! Because, you know, I could use the bathroom and stuff all the time."

The irreversible changes that accompany a serious illness and individual perceptions of these events influence current and future constructions of illness

meanings. One man identified a critical moment in time that was intimately intertwined with the circumstances surrounding his initial diagnosis. Lying on a bed in a hallway without the comforting presence of others he spoke of feeling very vulnerable and “terribly alone”:

All this was coming down on top of me. So at that particular moment . . . I didn't feel very good. I mean I was crying, I was really, really wiped out. And I was at the lowest end that I could ever be. And (pause) there wasn't anybody there.

The speed with which some participants had to move from becoming aware of reduced kidney functioning to beginning dialysis left them with very little time to place the critical event in a meaningful context: “But I wasn't expecting to come on dialysis within a month or so. That was an awful shock . . . it came overnight to me.” Some never quite adjusted because of the profound changes experienced in health status:

It was hard to accept because I was never sick a day in my life. (pause) I'm not one to be sick. And then just like that someone told you that something different was wrong. It was hard to take. (pause) I can't spend the rest of my life like this.

The presence of illness symptoms due to the interactive effects of co-morbid diseases (e.g., diabetes, cardiac, pulmonary) with ESRD and the unpredictable effects of treatment protocols (e.g., lifestyle adjustments, dialysis) on physical functioning also had notable effects on illness meanings. One woman who had been quite ill with diabetic nephropathy for an extended period of time attributed the marked improvement in her health and overall well-being to

dialysis: "I was so sick I couldn't keep my head up And it [*dialysis*] brought me around 100%. I've been on it now about five months and I feel like a brand new woman." Most participants who were aware of a significant decline in their health looked favourably upon the importance of starting hemodialysis.

But by the time I got here I prayed to get in here because I was so sick. Because I came from Coronary Care.

Well, I was deteriorating. Actually when (doctor) told me I couldn't go [*vacation*], I said, 'Thank goodness. I don't think I'm well enough to go'. . . . At that time I realized that I was going downhill But still, it was a disappointment of course.

There were some, however, who recognized a deterioration in their physical health but failed to grasp the full significance of illness symptoms. One young woman articulated this very well.

When I came in that day that they told me that I was going to have it [*dialysis*]. They said, 'Well, you know, you're really sick and your levels are really up. We don't like for diabetics to get too sick before we start them.' And I was like, 'I'm not sick.' And in the meantime I knew that I was sick I knew it wasn't normal that I couldn't eat and I was throwing up all the time. And I was sleeping at least 14 or 15 hours a day. . . . I knew none of that was normal I didn't fully understand.

When the initial movement from feeling physically unwell to an improved or stable state was replaced by declining physical health (e.g., excessive fluid, reduced energy, breathing problems, walking difficulties, etc.), illness meanings were altered significantly with the gradual erosion of newly formed standards for health and well-being. One man described how his initial experiences with feeling physically well contrasted sharply with his current health status (i.e.,

increased fatigue, pain and breathing difficulties upon walking due to coronary blockages): "I can't walk any distance The last year or so it's worse. . . . Oh, them first years, like I said, number one, I didn't mind it a bit."

Appraisal of treatment. Most participants had some understanding of treatment protocols and their importance. Limited knowledge early in the treatment cycle often stimulated a chain of events that had far-reaching implications for the person. One man's description of his first encounter with hemodialysis captures his lack of readiness for this experience:

I was wondering if they were going to ship me out to outer space. When I came in and I saw all of those patients and machines going and noise making, you know. It was frightening because I was sick at the time too.

With increased understanding of machine functioning, patients came to view hemodialysis as a lifeline that either enhanced or diminished the quality of life. One woman described how she became "more comfortable with it" as her knowledge increased: "The positive thing is, it's keeping me alive And I'm starting to learn a bit about it." Another lady who had encountered numerous problems with her illness and treatment viewed her situation in the following manner: "You know it seems like I don't get any breaks. Every time they [*nurses/physicians*] touch me something goes wrong I'm telling you I'm after going to hell and coming back." Another patient who felt that dialysis had compromised his lifestyle (i.e., "I lost all my privileges.") resigned himself to the inevitable: "It's either this or the boneyard, one of the two."

Although most were aware of long and short term benefits and complications of treatment protocols and could differentiate between feeling states during and following treatment, meaning constructions varied depending on perceptions about whether the self or others could control negative effects (i.e., exhaustion, breathing difficulties, headaches, muscle cramping, itching and hypotension). One man who fought recommended lifestyle restrictions and ignored the warning signs of declining physical health for about ten years, eventually came to recognize the consequences of his behaviours:

I used to overdo everything and it finally caught up to me. And my heart got enlarged and that's through too much fluid, and there was 6 or 7 kilos on me all the time. I used to brag about it. I said, 'It doesn't bother me one bit.' Not thinking about what it was doing to me inside.

Another participant described her constant battle with the negative effects of dialysis (e.g., needling, nausea, headaches) and how this influenced her perception of treatment: "And like a lot of days you get a headache and stuff, and it's really bad They [*doctors, nurses*] can't do nothing for you Cause there's only certain things that they can give you over there [*dialysis unit*].

Ambivalence - knowing versus doing. Ambivalence, the dominant property in this category, was defined in terms of forces/barriers to acceptance of illness and treatment requirements. With increased understanding and acceptance of ESRD and treatment protocols, participants indicated that they became more attentive to treatment protocols and modifications or changes, and technical and physiological problems. Some understood and accepted treatment

regimens: "I just cut it out. I stopped eating those things before I went on the machine, the potassium was there so I just [pause]. Anything with the potassium in it at all I just hardly touch." However, for others, there was evidence of a dichotomous relationship between knowing and doing. For one young man, cognitive awareness of the importance of dietary restrictions for buffering treatment effects and promoting health did not always concur with wants/desires or actual behaviour:

I find the fluid part the hardest because I love to drink icewater. And you know, if you drink too much the next time you come in it's going to be a harder dialysis for you. You know, your body just can't take it.

Another man indicated that it takes courage to change and adjust when confronted with ESRD. He also stressed the importance of having adequate information and understanding to successfully implement recommended lifestyle changes: "Because if you abuse them things [food and drink] well . . . I think there needs to be possibly, a better training, a better understanding, for the people who are on dialysis." The implication was that the mere provision of information is not enough. One man readily admitted why he did not follow recommended diet restrictions:

. . . like if you followed that [*diet regimen*] you'd probably starve to death . . . The wife tried to follow it like the Bible. If you followed it you'd never get enough money to pay for it. You know what I mean with two different diets in the house, or three.

To understand the experience of socialization into the dialysis-world one must come to appreciate how taken-for-granted self-indulgences may become a

matter of life and death. Despite encountering a number of medical complications and “bad” experiences while on dialysis (i.e., seizures, muscle cramping), one man was determined not to “let go of” the few pleasures he enjoyed. His attitude toward the treatment restrictions (e.g., food and fluid) was that they would not make any difference to his health or the quality of his life: “There’s nothing that can be done about it now anyway. So I mean, the only thing that I got to look forward to whatever time I got left I got to do it on the machine.”

Experiences with critical events (e.g., hypotension, actual/potential loss of access site, etc.) moved individuals to an higher level of self-awareness. Such experiences were strong motivators helping patients assume a more active role in managing regimens by seeking immediate attention for problems from health care providers, and inquiring about reasons for treatment errors and changes in health status. One woman commented on how she became more attentive to variable feeling states and machine functioning following a hypotensive event: “You must be alert when you are into something like this. You know, you can’t just be careless and not watch things.” Others were able to make the required changes and monitor the impact on physical health status:

That’s probably why my blood pressure hasn’t dropped because I’m really careful about my weight I do know when I have my limit [*fluid*] And I’m always watching my blood pressure because when my blood pressure starts to go up that means that I have fluid on.

Interrelationships Among Theoretical Constructs

The emerging theory suggests that redefinition of self, quality of supports and meanings of illness and treatment exert independent and interactive effects on perceived/actual quality of outcome (i.e., physical, social, emotional, and psychological functioning). Based on theoretical insights gleaned from the data, it is postulated that "critical turning points" are the common threads intersecting and joining the theoretical constructs defining a person's experiences with ESRD and hemodialysis. The proposed interrelationships among the theoretical constructs are outlined in Figure 1.

Critical turning points result from the meanings attributed to "critical events" that surface periodically during the illness/treatment experience. Critical events are defined as interactive experiences that may create a deep and lasting impression. These events may have either positive or negative implications for the person. Examples of critical events that have a negative impact include illness-related losses (e.g., renal failure, loss of alternate treatment modality, declining health status and well-being, etc.), treatment-related losses (e.g., access site, travel, time, strength, sleep deprivation, comfort, etc.), loss of supports (fellow patients, family, friends, trust and confidence in nurses/physicians, etc.), and loss of old self (e.g., self-worth, sense of control, independence, social self, financial security). Instances of positive critical events include physical health gains (e.g., improved functioning, increased stamina,

high energy levels, etc.), emotional and psychological stability (e.g., positive attitude, less uncertainty and stress, hope, empowerment, etc.), building supportive relationships (e.g., fellow patients, family, nurses, physicians, etc.), and adapting to a new normal (e.g., self-worth, sense of control, independence, social self, financial security). What is important for the instigation of critical turning points is the degree to which events, singularly or cumulatively, in one area (supports, illness/treatment, self) influence meaning constructions in another.

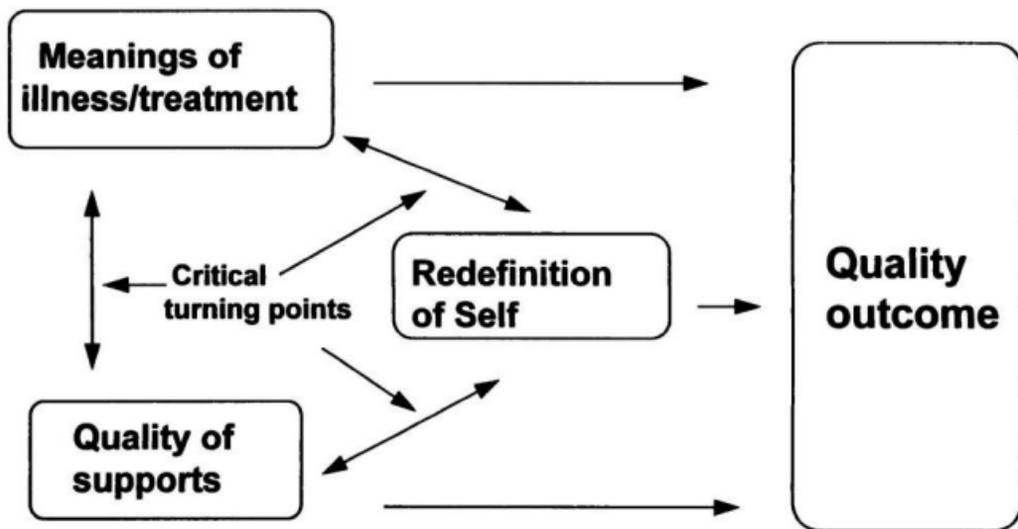


Figure 1. The Proposed Model of Patients' Perceptions of their Experiences with Hemodialysis and the Interrelationship Between the Major Constructs and the Critical Turning Points

A couple of illustrations might clarify how critical turning points forge relationships among the theoretical constructs. Despite feeling somewhat scared and uncertain about what hemodialysis involved, one woman assumed a positive attitude and eventually adjusted to the treatment routine. One significant factor that seemed to facilitate coping was the high value placed on maintaining a normal life and not letting dialysis gain control. Critical events such as being exposed to extremely sick patients and seeing others experience a sudden drop in blood pressure left her with a lasting impression. These experiences made her more cognizant of her vulnerability for unpredictable events and the need to become more vigilant while on dialysis (i.e., monitor feeling states, timing of treatment interventions): "I might doze for a few minutes but I don't sleep on the machine. I like to be awake But I think my worse fear is getting really sick, or something, or my blood pressure goes so low that I'll be sick." By trying to follow recommended treatment regimes as closely as possible and assume greater self-care responsibilities (i.e., watching diet and fluid restrictions), she chose to integrate required changes into her daily norm so they would not pose threats to the self. When one comes to terms with the fact that uncertainty is inherent in living with the illness and treatment, greater acceptance is possible.

Hypotensive events also generated critical turning points because the person may come face-to-face with his/her own vulnerability. Often these events impress upon the person the need to be more vigilant about changing feeling

states, healthy behaviors, and the actions of health care providers. The data suggest that the person who experiences these events periodically has a greater psychological and emotional reaction than one who experiences them rarely.

A number of participants who experienced a sudden drop in blood pressure identified the experience as a critical event. While this is a physiological event that may be anticipated or unanticipated, depending upon the track record of the person's time on dialysis, it is also a psychological event that is appraised cognitively first, and emotionally second. The cognitive appraisal may attribute responsibility to the quality of formal supports (i.e., removal of too much fluid or its removal too quickly during dialysis, malfunctioning equipment), or the meaning of illness and treatment for the self (i.e., not adhering to fluid and diet restrictions, or a declining physical health status). Emotionally one identifies the feeling states of fear, anxiety, and uncertainty (i.e., terrifying experience comparable to dying, fearing for one's life, inability to control the event's inception but possibly its severity). Some individuals may be empowered to assume personal responsibility for recognizing and hopefully reducing the severity of the event (i.e., attentive to feeling states that constitute warning signs, alerting the nurse when detecting a change in physical status, ensuring that blood pressure readings are taken regularly). Others may be so terrified and anxious about the event's reoccurrence, that they are in a constant state of tension and hyper anxiety while on dialysis (i.e., over-attentive to feeling states, constantly seeking

attention from the nurses - demanding).

When the impact of illness and treatment events were of sufficient magnitude to trigger a critical turning point, the person was often forced to reevaluate the self. The concept of a new self evolved as meanings of illness and treatment were altered by changing situational, personal and environmental factors. Not everyone was able to let go of the remembered "old self" and adapt to the evolving "new self" confronted at different phases in the illness trajectory. The diminished emotional and psychological functioning and the perceived decline in physical health resulting from a critical event often undermined the ability to accept and adjust to the evolving meanings of illness and treatment. Even those who seemed to have achieved some "sense of normalcy" continued to deal with the uncertainty of critical events.

Redefinition of the self did not occur in isolation from others. Although losses and gains for the self are individual specific, they derive meaning from the variant social contexts for activities and relationships. Encounters with others from different social worlds (e.g., family, friends, health care providers, etc.) served as constant reminders of the widening gap between the new self and the old self. The sense of self was severely hampered when major upheavals (e.g., loss of job, move to a new location to access dialysis, etc.) resulted in reduced supports. However, if the person was successful in forming alternate relations to replace what had been lost, there was a greater possibility of adapting to a new

normal. One man's story about having to relocate to access dialysis illustrates the crucial role played by supports in facilitating adjustment to a new normal. Two critical events - failed attempt at home dialysis and wife's difficulty adjusting to lifestyle changes following relocation - created a critical turning point that had major repercussions for him. Confronted with limited options, he adjusted by making the decision to live in a hostel during the week and commute home on the weekends. This was seen as one way to maintain some semblance of a normal life with family and friends. Although this new way of being-in-the-world presented him with many challenges and difficulties, he tried to cope by focusing on the positives ("This is now and this is it. I have to put up with it You got to take it one day at a time, yeah. And look forward for **Friday** to come.") and hoping that someday he would either receive a kidney transplant or have hemodialysis available closer to home. An additional source of comfort and support surfaced when he became friends with a fellow patient from the same area and living under comparable conditions.

Other participants discussed the importance of supports in promoting adaptation to a new normal. One woman indicated that without the support and care provided by nurses, doctors and other health care providers (i.e., social worker), she would find it difficult to accept the restrictions and negative effects of hemodialysis. Positive interactions with the dialysis staff, on both a personal and professional level, enhanced her comfort and ability to deal with problems:

"The nurses, they talk to you a lot. They help you with your problems over there a lot too." Although she noted that adjusting to dialysis was time dependent and required encouragement and support from others, she acknowledged that a great deal of responsibility rested with herself (i.e., assuming responsibility for acquiring knowledge about dialysis care, implementing appropriate monitoring measures, accepting the illness and dialysis treatment).

Some participants never quite adjusted to constant threats to the self imposed by their illness and treatment. The uncertainty associated with exposure to predictable/unpredictable critical events escalated the intensity of vulnerable feelings along the illness/treatment trajectory. For some the critical events resulting from encounters with the health care system reinforced fears that the self was threatened. One woman identified a number of critical events during dialysis that became critical turning points for her. When it was hectic on the dialysis unit (i.e., overcrowded with patients, frequent alarms emitted by the machine), she became stressed and fearful for her well-being. What impeded her adjustment to and acceptance of dialysis most was exposure to fellow patients illness episodes and unsanitary environmental conditions (e.g., blood spills and dirty surroundings). Besides the turmoil on the dialysis unit, this woman had to endure frequent headaches during dialysis and on non-dialysis days: "Before I went on the machine I never had these headaches. And now they're just completely, ever since I had pneumonia, everyday. They don't stop."

Because she continuously had to deal with ill-feelings, it became a constant battle to adapt to this new normal (i.e., going home and having to crawl into bed) and find the strength to "keep going". Also, general unwell feelings (e.g., pain, fatigue, nausea) compromised the quality of her life (i.e., not well enough to do things or socialize with friends). The only positives that she could attribute to dialysis was its lifeline ("It's keeping me alive.").

Another young woman identified a number of critical events that occurred over the years (e.g., dialysis treatment errors, etc.) that finally resulted in a critical turning point from one of complete trust in health care providers' care to one of doubt: "I don't want to die for some stupid error that could have been prevented." Altered levels of comfort and sense of trust with nursing and medical care negatively impacted her emotional/psychological well-being. Consequently, she gained a heightened sense of awareness about the importance of being more attentive and monitoring changes in treatment routines. Finding it increasingly difficult to adjust to the perceived diminished quality of supports during dialysis, the only acceptable solution to her current situation was to pursue other viable options: "I'm to the point now that I just can't wait to get out of here I figured that [*transplant*] that's my only hope. My only chance for anything."

In summary, the evolving meaning of illness and treatment and the quality of interactions with significant others (family, friends, fellow patients, health care

providers) in different situational contexts had important implications for the self. The heightened uncertainty associated with critical events resulting from illness and treatment or encounters with others posed a continuous challenge for the self. The roller-coaster ride forged a new sense of being-in-the-world with the abnormal seen as normal, the unpredictable expected, and the taken-for-granted elusive.

Discussion

The meanings of illness and treatment (i.e., illness severity, effectiveness of technical support, treatment effects) and the quality of supports (e.g., family, friends, fellow patients, health care providers) were important factors influencing redefinition of self (i.e., adjustment to and acceptance of illness chronicity and treatment regimes). Critical events that occur in each area defining the person's experience with ESRD and hemodialysis have the potential to generate critical turning points. These "critical turning points" facilitate or impede acceptance of illness and treatment, move the person to a higher or lower level of awareness, or alter perceptions of supports, learning needs and healthy behaviours.

The accompanying uncertainty about the future and the multitude of physical changes resulting from illness and treatment effects began to transform the self over time. Routines were rearranged to accommodate treatment regimens (i.e., e.g., fluid and food restrictions) and accessing dialysis (e.g.,

scheduling of treatment, transportation concerns). For the majority of patients relationships with family and friends were altered (i.e., decreased social interaction, greater dependency, avoidance, enhanced relationships). Coping effectiveness over time was influenced by learning about the illness and treatment parameters and effects which prepared the person to appreciate the changes required of the self, especially concerning interactions with informal and formal supports. For the majority of participants the changes were sudden and profound. Emotional/psychological adjustments were only superseded in intensity by illness severity and/or ensuing complications.

Critical turning points are comparable to a gestalt whereby a person recognizes for the first time that: a) medical care is not always free from error or health promoting (i.e., induced illness states - cramps, sudden drop in blood pressure), b) life as they knew it has been significantly changed or altered (i.e., loss of kidney [s] and/or kidney function, dependence on dialysis machine to perform normal kidney function, restricted lifestyle - diet, activity tolerance, place of residence, travel), and c) the responsibility for knowing, implementing and monitoring treatment regimens rests with the self (i.e., the importance of knowing treatment protocols and implementing appropriate controls - monitoring, questioning, health promoting behaviors). In short, critical events, while external to the self, are also intimately connected to the new self that is unfolding by creating critical turning points. It is the person's response to the critical event

that may be important.

CHAPTER V

Discussion of Findings

This study was designed to explore patients' experiences with and perceptions of ESRD and hemodialysis, and the impact of critical events that occurred at different times in the hemodialysis cycle on perceptions of care quality or satisfaction with care. This chapter discusses the current study findings in terms of research findings identified from the relevant literature. The presentation is organized according to the dominant theoretical constructs generated during data analysis.

Living with ESRD and Hemodialysis

What clearly distinguishes the proposed theoretical model from previous models which conceptualize patients' experiences and outcomes (Bauman, 1991; Donabedian, 1988a, 1988b; Meyer, 1995; Peters, 1995) is the significance of the construct "redefinition of self". The current study suggests that changes in the meanings of illness and treatment and in the perceived quality of supports exert a powerful impact on how the self is being redefined. Redefinition of self is a result of patients' perceptions of the meanings of illness and treatment and the perceived quality of supports. Conversely, this redefinition also impacts on both of these constructs. Furthermore, each of the constructs may act independently of or interactively with each other (i.e., each influences and is influenced by the

other).

Although the theoretical constructs generated have been discussed previously in the qualitative literature dealing with how individuals experience a chronic illness (Kleinman, 1988; Charmaz, 1983, 1987; Conrad, 1987, 1990; Corbin & Strauss, 1987; Morse & Johnson, 1991; Robinson, 1993), the interactive relationships and the impact on quality of outcome have not been addressed. Further, limited attention has been given to how patients with ESRD and hemodialysis treatment experience and adjust to a new sense of self, as a result of the changes in illness, treatment, and supports (Kutner, 1987; O'Brien, 1983; Rittman, Northsea, Hausauer, Green, & Swanson, 1993).

Redefinition of Self

Study findings suggest that participants were in a constant battle with balancing uncertainty about their illness and the effects of treatment, while maintaining hope for improved health and a return to a normal life. While this struggle intensified during periods of ill health, it diminished with improved health. The constant emotional and psychological adjustments to changing health states played havoc with participants integration of a positive sense of self into their various social worlds. In the current study some participants made reference to the hope of regaining the worry free self experienced before diagnosis and commencement of hemodialysis. Others talked about how their lives had been

turned upside down since starting dialysis. Limited assessment of these findings was found in the hemodialysis literature (Charmaz, 1983; Kutner, 1987; O'Brien, 1983).

Despite the frustrations of dealing with an uncertain future because of constant physical, emotional, psychological and social changes, most participants indicated that they strived to maintain a positive attitude towards the illness, treatment restrictions, and reduced quality of life. Overall, all participants also maintained a realistic attitude about the future (e.g., transplant availability, stability of health status, long-term maintenance dialysis, death). Clearly the choice of fostering a positive outlook versus a pessimistic attitude towards end stage renal disease and hemodialysis was considered by the majority as a constructive buffering strategy in dealing with this life threatening and technology dependent chronic illness. One participant found that focusing on maintaining as normal a life as possible and preparing for a kidney transplant provided him with the incentive that facilitated acceptance of dialysis as a short-term measure. He perceived the positive approach to each critical encounter experienced as the catalyst that kept him going. Several researchers have identified the important role that positive thinking plays in helping patients cope with hemodialysis (Eichel, 1986; Ferrans & Powers, 1993; Gurklis & Menke, 1995; Hoothay et al., 1990; Kutner, 1987; O'Brien, 1983; Rittman et al., 1993).

While adapting to a new normal, participants struggled with desires/wants

and physiological requirements by assuming the burden of decision-making. It seems that with ESRD patients, who receive hemodialysis two to three times a week, it is not possible to ever regain a semblance of the former self free from dependency on a dialysis machine, or achieve a comparable level of wellness reflective of the "old" self. Participants dealt with their chronic illness and treatment restrictions by weighing the odds, implementing control measures, and trying to reframe the illness within as normal a life-context as possible. This tendency to engage in a normalizing process to engender the "lived world" with a sense of stability and predictability has been reported by others (Morse & Johnson, 1991; Robinson, 1993).

Quality of Supports

The meanings of illness and treatment for persons with ESRD are also continuously being redefined in response to others' (i.e., spouse, family, friends) reactions to illness manifestations (i.e., improving or worsening health status). Study participants expressed variable degrees of satisfaction with increasing dependency on technology, health care providers, and family and friends. Norman, Redfern, Tomalin, and Oliver (1992) suggest quality is a value judgement made by the self and is shaped by sociocultural forces. The concept of what constitutes quality will vary depending on perceptions, attitudes, rights, and personal beliefs.

In the current study participants defined quality of health care in terms of the skilled performance of nurses initiating dialysis and monitoring the dialysis-run, the timely and appropriate interventions of physicians, and the conduciveness of the dialysis environment. With increasing knowledge about treatment protocols and greater adjustment to the routine, most participants critically appraised care quality in terms of expected "norms". The majority of patients verbalized a desire to be cared for in a safe environment and in an efficient and competent manner. Others identified the need for promptness in starting and discontinuing hemodialysis, while others believed a more flexible schedule would improve life for them while receiving treatment for ESRD. The importance of building relationships based on trust and being cared for and valued as a human being were identified by many participants. Jones and Preuett (1986) discuss the "guarding" behaviours used by hemodialysis patients to monitor the quality of staff's care practices.

Study findings indicate that participants were generally satisfied with the quality of health care, giving fairly high ratings to the technical and interpersonal competency of nurses and physicians. Comparable findings are reported in the literature (Ferrans et al., 1987; Ferrans & Powers, 1993). Observed deficiencies in nursing care were rationalized in terms of staff shortage, ergonomics of the dialysis unit, and variant experience levels and attitudes of nurses, as reported by others (Kutner, 1987; Oberley, 1991a, 1991b; O'Brien, 1983; Pontin & Webb,

1996). Dissatisfactions with the quality of medical care were expressed as perceived problems with continuity, availability, and caring attitudes. This has also been reported by other investigators (Hall & Dorman, 1988a, 1988b; Oberley, 1991a; 1991b; Kutner, 1987; O'Brien, 1983; Siegal, Calysan, & Cuddihee, 1987). It can be argued that if the environment is non-conducive to promoting overall health, then patients are forced to adjust to hemodialysis under considerable stress (i.e., observing variable levels of acuity of fellow patients, experiencing the loss of fellow patients through transplant or death, receiving hemodialysis in cluttered environment which infringes on the patients' right to privacy).

The role that the health care setting plays in facilitating adjustment to treatment and illness is equally as important, but has received limited attention (Ferrans et al., 1987; Siegal, Calysan, & Cuddihee, 1987). Within the evolving relationship with health care providers, participants expressed an inherent desire to be treated in a humanistic manner, and cared-for, valued and accepted as a person. However, for the most part, dialysis nurses were more likely to be recognized for performing this aspect of care than physicians. The findings of this study clearly demonstrate patients expectations with regards to the level of nursing care. The value that dialysis patients place on nurses' caring attitudes, and being aware of the total person and his/her needs and concerns has been identified previously (Ferrans et al., 1987; Gurklis & Menke, 1995; Kutner, 1987; O'Brien, 1983).

Interactions with fellow patients also helped create an environment that counteracted the dehumanizing effects of hemodialysis technology. Participants identified the importance of the presence of a family-like atmosphere on the dialysis unit, and the provision of emotional and informational support by fellow-patients and their families. Kutner (1987) commented on the importance of the dialysis social world in providing a supportive family-like environment. In the current study fellow-patients shared information about illness and treatment symptoms, monitored machine functioning and unwell feeling states, and facilitated coping with illness and treatment. However, participants also identified negative consequences of maintaining close relationships with fellow-patients. Psychological stressors were associated with acute illness episodes or deaths of fellow-patients. Comparable findings have been reported by O'Brien (1983).

Participants also placed high value on the support provided by family and friends. Of particular significance was the provision of emotional support, and the assistance provided to help with the management of day-to-day treatment regimens (Gurklis & Menke, 1995; Kutner, 1987; O'Brien, 1983, 1990). Despite the conflicting evidence on the relationship between the quality of family support and patient compliance with treatment regimens (Christensen, Smith, Turner, Holman, Gregory, & Rich, 1992; Kutner, 1987; O'Brien, 1983, 1990), there is an emerging body of research suggesting that survival among ESRD patients is strongly influenced by the quality of family support (Christensen, Weibe, Smith, &

Turner, 1994; Gurklis & Menke, 1995; Kimmel, Weihs, & Peterson, 1993; Levinsky & Mesler, 1994; O'Brien, 1983).

Participants also acknowledged that family and friends tended to promote greater dependency in relations than desired. Gurklis and Menke (1995), O'Brien (1983) and Kutner (1987) also refer to this independence/dependence conflict within close relationships. In the current study participants also became increasingly aware of the impact of the illness and treatment requirements upon others (i.e., spouse, family, friends), and the need to protect them from the burden of care. The findings of Baldree, Murphy, and Powers (1982) indicated that the tendency of family and friends to display an overprotective attitude and excessive attention to the illness and treatment was a psychosocial stressor which generated feelings of self-consciousness and uneasiness.

Meanings of Illness/Treatment

Whether the diagnosis of ESRD was sudden or expected, study participants were not always prepared for the initiation of dialysis. The findings also indicate that in the early months feeling unwell, and limited understanding of treatment and the terminal nature of the illness created barriers to acceptance and adjustment. Comparable findings were reported by Kutner (1987) in a study of patients with ESRD.

Participants initial appraisal of the illness and treatment as separate and

distinct entities dissipated as symptoms of comorbid illness and treatment affects merged with those of ESRD. Although Rittman et al.'s (1993) findings indicate that integration of the dialysis machine alters perception of the physical self, these authors fail to consider the changing relationship in the meanings of illness and treatment over time. In the current study, as time on dialysis increased understandings about the workings of the machine, participants described how this form of treatment influenced the quality of their lives. The positive effects of treatment were improved physical health and the resulting ability to engage in regular activities (e.g., work, social, travel). As found by others (Baldree, Murphy, & Powers, 1982; Bihl, Ferrans, & Powers, 1988; Eichel, 1986; Ferrans & Powers, 1993; Gurklis & Menke, 1995; Lok, 1996) fatigue, general weakness, physical limitations, hypotension, muscle cramps, and pain and discomfort with needling of access site were the most frequently identified adverse effects or physiological stressors.

As participants moved along the illness trajectory, variant factors and/or critical events emerge to shape knowledge of illness and treatment, and the degree of attentiveness to treatment regimens. Critical events may, singularly or cumulatively, bring patients to a turning point, constituting a moment of truth. It is apparent from the data that patients who experience frequent illness episodes, and periodic access site or machine functioning problems have greater psychological and emotional difficulties than those who experience these events

rarely. Fife (1994) found that cancer patients ability to assimilate the impact of a critical event, place it in an appropriate context and adapt to its ensuing illness manifestations is dependent on their perceptions of the meaning of their illness.

Interrelationship among Constructs

The desire to maintain some degree of control and appear "normal" are often balanced against negative experiences consequential to dialysis treatment. The tendency to alter regimens is partially reflected in patient comments that imply a difference between knowledge/understanding and actual behaviour (i.e., frustration or difficulties with maintaining diet and fluid limitations during social activities, financial strain of diet, etc.). ESRD patients attempt to maintain some sense of control by modifying treatment plans, especially diet and fluid restrictions, to achieve maximal satisfaction while minimizing risk (Gurklis & Menke, 1995; Kutner, 1987; Montemuro, Martin, Jakobson, Mohide, Beecroft, Porterfield, & Ollinger, 1994; O'Brien, 1990; Rittman, Northsea, Hausauer, Green, & Swanson, 1993). Jones and Preuett (1986) investigated self-care activities for managing medical regimens in a sample ($N = 25$) of hemodialysis patients. These authors found that substituting fluids, food, and activities to achieve an acceptable balance was a common practice in this population.

With time the interaction of comorbid conditions and negative effects of dialysis increases awareness of deteriorating health and feelings of inadequacy

about the self or others abilities to control events. Some individuals are empowered to assume personal responsibility for detecting and hopefully reducing the severity of critical events during dialysis (i.e., attentive to changed feeling states and alerting the nurse/physician, ensuring regular monitoring of blood pressure, questioning procedures), while others are immobilized by tension and anxiety (i.e., over-attentive to feeling states, constantly seeking attention from the nurses). Studies focusing on the effectiveness of variant coping styles for managing physical and psychological stressors concur with these findings (Baldree et al., 1982; Gurklis & Menke, 1995; Lok, 1996). Montemuro et al.'s (1994) findings also suggest that patients level of knowledge and assertiveness, and health status influence their perceived or desired control over various aspects of care.

Summary

It is apparent from this study's findings that consideration of the meaning of treatment regimens for individual patients will provide useful insights into the variations observed in adherence to hemodialysis regimens. Rittman et al. (1993) assert that compliance issues in the hemodialysis patient population can only be addressed in a meaningful way by grasping a greater understanding of the contextual factors that influence individual experiences. Conrad (1987) suggests that although information is a valuable resource facilitating more

effective management of chronic illness, self-regulation of regimens should provide the framework for clinical interventions as opposed to compliance models.

In summary, when confronted with ones vulnerability and the limitations of technical care, there is a heightened awareness of the need to be more vigilant about changing feeling states, health promoting behaviors and the actions of health care providers. However, the research base on hemodialysis fails to consider the impact critical events discharge on perceived meanings of illness and treatment. There is a growing recognition among researchers of the importance of gaining a greater understanding of how meanings of illness and treatment are influenced by variant situational and sociocultural factors in order to provide more effective health care (Charmaz, 1987; Conrad, 1990; Fife, 1994; Kleinman, 1988; Morse & Johnson, 1991). Kleinman (1988) argues that failure to consider meanings of illness "disables the healer and disempowers the chronically ill" (p. 9).

CHAPTER VI

Limitations, Recommendations and Conclusions

This chapter presents the limitations of the study, recommendations for further research and conclusions based on the data.

Limitations of the Study

The study sample represents a cross section of the hemodialysis population of a large tertiary institution in the province of Newfoundland who met selected inclusion criteria and was Caucasian. The theoretical constructs identified in this study require further validation in other hemodialysis patient populations. However, the qualitative design arguably may compensate for the small sample size ($N = 36$).

Although participants were assured that physicians associated with their care would not have access to the audio taped interviews, responses to the interview questions may have been given in a socially acceptable manner due to fear of retribution or impact on care delivery. Further, responses may have been influenced by the approach used by the interviewer. The location of a majority of the interviews (i.e., a private room adjacent to the hemodialysis unit) may have impacted on the interview process (e.g., interruptions for monitoring purposes), although this did not appear to impact the flow of thought or conversation.

Theoretical generalizability (i.e., "the extent to which the findings of the

research may be applied to other situations or settings" Morse & Field, 1996, p.198) cannot be determined. The perspective of those who did not meet inclusion criteria has not been obtained.

Participants were asked to recall past events (e.g., initial diagnosis, positive and negative experiences that left an impression, etc.). The average length of time on hemodialysis was 2.66 years (Range = 0.25 - 12.25; SD = 3.24). It is conceivable that the ability to recall events or critical turning points may have diminished with the passage of time.

The generation of a formal theory is not possible in that a single substantive (empirical) theory is being assessed in the present study. However an important link has been forged through the development of this single substantive theory to a formal theory based on the data. Further research is required to determine the perceptions of health care providers and families of hemodialysis patients.

Recommendations for Further Research

Redefinition of self is a new perspective for understanding patients' experiences with ESRD and hemodialysis and thus may impact on the way health care providers deliver care. Although there has been a growing awareness of the complexities of risk factors affecting patient outcomes, limited efforts have been made to explore the total experience of patients living with

ESRD and hemodialysis treatment. In the absence of a unified theory on the experience of ESRD and hemodialysis treatment, a multi-dimensional model based on the expectations and perceptions of the primary groups involved (i.e., health care providers, families and patients) is required to guide health care providers. A greater focus on the interrelationship of quality of supports, meanings of illness and treatment, and redefining the self, with quality of outcome data is required. Further exploration of the concept of redefining the self is necessary. Also, there is an aspect of this category or perhaps related to it that does not emerge strongly from the current study findings. That is as people define themselves they also reassess their self-worth (e.g., Am I still a valuable and worthwhile person, am I still an important contribution to my life, to my family, to other people?). The concept of self-worth is central to peoples' happiness and comfort with they are in the world and quite conceivably may influence survival (i.e., Why survive or take care of myself if I believe I am worthless?). This aspect of self-worth may also create a pathway for the development of a variety of interventions aimed at having patients explore, realize and affirm their own value, despite and even sometimes because of their illness.

Consideration should be given to combining quantitative and qualitative methods of research design to capture the experience of ESRD and hemodialysis treatment effects on the family and health care providers. It is

recommended that further research be conducted to explore the perceptions of families and health care providers. Also, the potential influence of the quality of informal and formal supports on survival among the hemodialysis patient population requires further attention. If quality of supports impacts the quality of outcomes, the identification of appropriate interventions to improve quality are necessary.

Surveys of individuals experiencing a chronic illness and the interactive effects of treatment regimens (i.e., technical and interpersonal) can provide useful information on the quality of health care. However, the rich database generated from this study has clinical significance from the point of view that the data is patient-specific and addresses common themes of the hemodialysis patient population. Further the findings suggest a need to develop an effective monitoring tool that is sensitive enough to detect subtle changes in each of the three categories identified (i.e, quality of supports, redefining the self, meanings of illness and treatment) and their interactive effects. A monitoring instrument would enable health care professionals to identify critical events and their magnitude of impact, as they occur at various stages of the illness trajectory. The overall goal is to construct an instrument based on items grounded in the data that are psychometrically valid and reliable, capture and measure the dimensions of critical events associated with ESRD, its treatment, and quality of health care delivered.

The constructs identified in the current study suggest that working on attitudinal and behavioural change through various educational strategies (i.e., providing knowledge and promoting the importance of lifestyle modifications) is not sufficient. Other equally important aspects of a person's varied social worlds and the self must include experiences of families and/or spouses (i.e., What impact does patient supports exert on how the person adjusts to the many changes resulting from living with ESRD and renal replacement therapy?). This area is especially important given the potential/actual impact of acceptance of the new self on morbidity and mortality outcomes. For health care providers, this means broadening the scope of care beyond individuals to include families and spouses.

Health care professionals need to gain a greater understanding about patients' subjective experiences of living with ESRD to ensure appropriate identification of potential/actual problem areas and individual needs. The application of appropriate interventions to meet individual and group needs may facilitate emotional and psychological adjustment to ESRD and hemodialysis treatment.

Conclusions

The purpose of this study was to explore the meanings of patients' experiences with ESRD and hemodialysis and the perceived quality of care. A

secondary purpose was to identify when critical events are most likely to occur and what resulting impact they may or may not have on perceptions of care quality or satisfaction with care. Despite the limitations of the study design the following conclusions have been reached based on the data analysis and study findings.

Patients' perceptions of their experiences on hemodialysis revolve around psychological adjustment to illness chronicity, the presence of supports (particularly in facilitating this adjustment), acceptance of treatment regimens, and a trade off between desired/expected versus actual treatment outcomes. Inadequate knowledge of the harmful effects of not following a prescribed regimen or the lack of motivation to engage in health promoting behaviours reflect only one aspect of the issue. There also exists strong influences from the various social worlds (i.e., dialysis unit, dialysis unit staff, fellow patients, families, friends) of the person with ESRD which are often labelled social determinants of health. Health care providers need to consider these influences on healthy behaviours by exploring further the lived experiences of individuals with ESRD. The perceived degree to which one's life has been altered permanently creates uncertainties about future health status and what this means for a normal life. The uncertainties (e.g., financial, relationships, social activities, etc.) may prove to be significant stressors affecting adaptive coping (i.e., use of non-health promoting behaviour to deal with stress and maintain an image of normalcy). A

sense of control over stressors or perceived power to manage and/or change things may be important components in the redefinition of self.

REFERENCES

- Annual Report 1997, Volume 1: Dialysis and Renal Transplantation, Canadian Organ Replacement Register, Canadian Institute for Health Information, Ottawa, Ontario, March 1997.*
- Abram, H. S. (1977). Survival by machine: The psychological stress of chronic hemodialysis. In R.H. Moss. (Ed.) *Coping With Physical Illness*, New York: Plenum Medical Book Co.
- Acchiardo, S. R., Moore L. W., & La Tour P. W. (1983). Malnutrition as the main factor in the morbidity and mortality of hemodialysis patients. *Kidney International*, 24(Suppl. 16), 199-203.
- Albrecht, K., & Zemke, R. (1990). *Service America*. New York, NY: Warner Books Inc.
- Baldree, K. S., Murphy, S. P., & Powers, M. J. (1982). Stress identification and coping patterns in patients on hemodialysis. *Nursing Research*, 31(2), 107-112.
- Barth, R. H. (1993). Urea modelling and Kt/V: a critical appraisal. [Review]. *Kidney International*, 43(Suppl. 41), 252-260.
- Bauman, M. K. (1991). The importance of outcome measurement in quality assurance. *Holistic Nursing Practice*, 5(3), 8-13.
- Bergstrom, J. (1985). Uremia is an intoxication. *Kidney International*, 28(Suppl. 17), 2 - 4.
- Bihl, M. A., Ferrans, C. E., & Powers, M. J. (1988). Comparing stressors and quality of life of dialysis patients. *American Nephrology Nurses Association*, 15(1), 27-36.
- Blake, C. W., & Courts, N. F. (1996). Coping strategies and styles of hemodialysis patients by gender. *American Nephrology Nurses Association Journal*, 23(5), 477-482, 507.
- Bliersbach, C. (1988). Quality assurance in health care: Current challenges and future directions. *Quality Review Bulletin*, 14(10), 315-319.
- Burrows -Hudson, S. (1995). *Nephrology clinical outcomes Part 1:*

Mortality, morbidity, adequacy of treatment, and quality of life. *American Association of Nephrology Nurses*, 22(2), 113-121.

Burton, H. J., Kline, S. A., Lindsay, R. M., & Heidenheim, P. (1988). The role of support in influencing outcome of end-stage renal disease. *General Hospital Psychiatry*, 10(4), 260-266.

Capelli, J. P. (1994). Implementing organizational systems to measure outcome-related processes of end-stage renal disease care. *American Journal of Kidney Diseases*, 24(2), 346-354.

Charra, B., Calemard, E., Ruffet, M., Terrat, J. C., Vanel, T., Laurent, G. (1992). Survival as an index of adequacy of dialysis. *Kidney International*, 41(5), 1286-1291.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168-195.

Charmaz, K. (1987). Struggling for a self: Identity levels of the chronically ill. In P. Conrad & J. Roth (Eds.), *The Experience and Management of Chronic Illness. Research in the Sociology of Health Care: Vol 6* (pp. 283-321). Greenwich, CT: JAI Press.

Chenitz, W. C., & Swanson, J. M. (1986). Qualitative research using grounded theory. In W. C. Chenitz, & J. M. Swanson (Eds.) *From practice to grounded theory: Qualitative research in nursing*. (pp.3-15) New York: Addison-Wesley.

Christensen, A. J., Smith, T. W., Turner, C. W., Holman, J. M., Gregory, M. C., & Rich, M. A. (1992). Family support, physical impairment, and adherence in hemodialysis: An investigation of main and buffering effects. *Journal of Behavioral Medicine*, 15(4), 313-325.

Christensen, A. J., Wiebe, J. S., Smith, T. W., & Turner, C. W. (1994). Predictors of survival among hemodialysis patients: Effect of perceived family support. *Health Psychology*, 13 (6), 521-525.

Cleary, P. D., & McNeil B. J. (1988). Patient satisfaction as an indicator of quality care. *Inquiry*, 25(1), 25-36.

Conrad, P. (1987). The experience of illness: recent and new directions. In P. Conrad and J. Roth (Eds.), *The Experience and Management*

of Chronic Illness. *Research in the Sociology of Health Care Vol 6* (pp. 1-31). Greenwich, CT: JAI Press.

Conrad, P. (1990). Qualitative research on chronic illness: A commentary on method and conceptual development. *Social Science and Medicine*, 30(11), 1257-1263.

Corbin, J., & Strauss, A. L. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. In P. Conrad & J. Roth (Eds.) *The Experience and Management of Chronic Illness. Research in the Sociology of Health Care, Vol 6* (pp. 249-281). Greenwich, CT: JAI Press.

Donabedian, A. (1980). *The definition of quality and approaches to its assessment*. Ann Harbor, Michigan: Health Administration Press.

Donabedian, A. (1988a). Quality assessment and assurance: Unity of purpose, diversity of means. *Inquiry*, 25(1), 173-192.

Donabedian, A. (1988b). The quality of care: how can it be assessed? *Journal of the American Medical Association*, 260(12), 1743-1748.

Eichel, C. (1986). Stress and coping in patients on CAPD compared to hemodialysis patients. *American Nephrology Nurses Association Journal*, 13(1), 9-13.

Eilwood, P. M. (1988). A technology of patient experience. [Report]. *New England Journal of Medicine*, 318(23), 1549-1556.

Fernandez, J. M., Carbonell, M. E., Mazzuchi, N., & Petruccioli, D. (1992). Simultaneous analysis of morbidity and mortality factors in chronic hemodialysis patients. *Kidney International*, 41(4), 1029-1034.

Ferrans, C. E., Powers, M. J., & Kasch, C. R. (1987). Satisfaction with health care of hemodialysis patients. *Research in Nursing & Health*, 10 (6), 367-374.

Ferrans, C. E., & Powers, M. J. (1993). Quality of life of hemodialysis patients. *American Nephrology Nurses Association Journal*, 20(5), 575-581.

Fife, B. L. (1994). The conceptualization of meaning in illness. *Social Science & Medicine*, 38(2), 309-316.

- Flaherty, M. J., Sr., & O'Brien, M. E. (1992). Family styles of coping in end stage renal disease. *American Nephrology Nurses Association Journal*, 19(4), 345-349, 366.
- Foley, R. N., Parfrey, P. S., Hamett, J. D., Kent, G. M., Martin, C. J., Murray, D. C., & Barre, P. E. (1995). Clinical and echocardiographic disease in patients starting end-stage renal disease. *Kidney International*, 47(1), 186-192.
- Foley, R. N., Parfrey, P. S., Hamett, J. D., Kent, G. M., Murray, D. C., & Barre, P. E. (1996a). Impact of hypertension on cardiomyopathy, morbidity and mortality in end-stage renal disease. *Kidney International*, 49(5), 1379-1385.
- Foley, R. N., Parfrey, P. S., Hamett, J. D., Kent, G. M., Murray, D. C., & Barre, P. E. (1996b). Hypoalbuminemia, cardiac morbidity, and mortality in end-stage renal disease. *Journal of the American Society of Nephrology*, 7(5), 728-736.
- Foley, R. N., & Parfrey, P. S. (1997). Cardiac disease in chronic uremia: Clinical outcome and risk factors. *Advances in Renal Replacement Therapy*, 4(3), 234-248.
- Fosbinder, D. (1994). Patient perceptions of nursing care: An emerging theory of interpersonal competence. *Journal of Advanced Nursing*, 20(6), 1085-1093.
- Fuchs, J., & Schreiber, M. (1988). Patient's perceptions of CAPD and hemodialysis stressors. *American Association of Nephrology Nurses*, 15(5), 282-285, 300.
- Fukunishi, I. (1993). Psychological problems of kidney transplantation: Satisfaction with dialysis therapy and desire for transplantation in hemodialysis patients. *Nephron*, 64(1), 146-149.
- Glaser, B. G. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Glaser, B. G. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.

Gotch, F. A., & Sargent, J. A. (1985). A mechanistic analysis of the National Cooperative Dialysis Study (NCDS). *Kidney International*, 28(3), 526-534.

Greeneich, D. (1993). The link between new and return business and quality of care: Patient satisfaction. *Advanced Nursing Science*, 16(1), 62-72.

Gurklis, J. A., & Menke, E. M. (1988). Identification of stressors and use of coping methods in chronic hemodialysis patients. *Nursing Research*, 37(4), 236-239, 248.

Gurklis, J. A. & Menke, E. M. (1995). Chronic hemodialysis patients' perceptions of stress, coping, and social support. *American Nephrology Nurses Association Journal*, 22(4), 381-388.

Hall, J., & Dornan, M. C. (1988a). Meta-analysis of satisfaction with medical care: Description of research domain and analysis of overall satisfaction levels. *Social Science and Medicine*, 27(6), 637-644.

Hall, J. A., & Dornan, M. C. (1988b). What patients like about their medical care and how often they are asked: A meta-analysis of the satisfaction literature. *Social Science and Medicine*, 27(9), 935-939.

Hall, J. A., Rotor, D. L., & Katz, N. R. (1988). Meta-analysis of correlates of provider behavior in medical encounters. *Medical Care*, 26(7), 657-672.

Harnett, J. D., Foley, R. N., Kent, G. M., Barre, P. E., & Parfrey, P. S. (1995). Congestive heart failure in dialysis patients: Prevalence, incidence, prognosis and risk factors. *Kidney international*, 47(3), 884-890.

Hays, R. D., Kallich, J. D., Mapes, D. L., Coons, S. J., & Carter, W. B. (1994). Development of the Kidney Disease Quality of Life (KDQOL) Instrument. *Quality of Life Research*, 3(5), 329-338.

Hilton, B. A., & Starzomski, R. (1994). Family decision making about living related kidney donation. *American Nephrology Nurses Association Journal*, 21(6), 346-354.

Hinds, P. S., Scandrett-Hibden, S., & McAulay, L. S. (1990). Further assessment of a method to estimate reliability and validity of qualitative research findings. *Journal of Advanced Nursing*, 15(4), 430-435.

Holman, H. R. (1993). Qualitative inquiry In medical research. *Journal of Clinical Epidemiology*, 46(1), 29-36.

Hoothay, F., DeStefano, A. E., Leary, E. M., Foley-Hartel, T. C. (1990). Life satisfaction and coping of diabetic hemodialysis patients. *American Nephrology Nurses Association Journal*, 17(5), 361-364.

Iseki, K., Kawazoe, N., & Fukiyama, K. (1993). Serum albumin is a strong predictor of death in chronic dialysis patients. *Kidney International*, 44(1), 115-119.

Jirsch, D. (1993). Patient-focused care: The systemic implications of change. *Healthcare Management Forum*, 6(4), 27-32.

Jones, L. C., & Preuett, S. G. (1986). Self-care activities and processes used by hemodialysis patients. *American Nephrology Nurses Association Journal*, 13(2), 73-79.

Kimmel, P. L., Weihs, K., & Peterson, R. A. (1993). Survival in hemodialysis patients: The role of depression. *Journal of the American Society of Nephrology*, 4(1), 12-27.

Kimmel, P. L., Peterson R. A., Weihs, K. L., Simmens S. J., Boyle D. H., Umana W. O., Kovac J. A., Alleyne S., Cruz, I., & Veis, J. H. (1996). Psychological functioning, quality of life, and behavioral compliance in patients beginning hemodialysis. *Journal of the American Society of Nephrology*, 7(10), 2152-2159.

Kleinman, A. (1988). *The Illness Narratives*. New York: Basic Books.

Koch, T. (1994). Beyond measurement: fourth-generation evaluation in nursing. *Journal of Advanced Nursing*, 20(6), 1148-1155.

Kurtin, P. S. (1995). Assessing patient outcomes with higher hematocrit levels. *American Journal of Kidney Diseases*, 25 (Suppl. 1), 8 -11.

Kutner, N. (1987). Social worlds and identity in end-stage renal disease. In P. Conrad and J. Roth (Eds.), *The Experience and Management of Chronic Illness. Research in the Sociology of Health Care Vol 6* (pp.33-71). Greenwich, CT: JAI Press.

Kutner, N. G. (1994). Assessing end-stage renal disease patients'

functioning and well-being: measurement approaches and implications for clinical practice. [Review]. *American Journal of Kidney Diseases*, 24(2), 321-333.

Larrabee, J. H. (1995). The changing role of the consumer in health care quality. *Journal Nursing Care Quality*, 9(2), 8-15.

Larrabee J. H. (1996). Emerging Model of Quality. *Image: Journal of Nursing Scholarship*, 28(4), 353-358.

Laupacis, A., Muirhead, N., Keown, P., & Wong, C. (1992). A disease-specific questionnaire for assessing quality of life in patients on hemodialysis [published erratum appears in *Nephron* 1992;61(2):248]. *Nephron*, 60(3), 302-306.

Levinsky, N. G., & Mesler, D. E. (1994). Measuring, managing, and improving the quality of end-stage renal disease care. *American Journal of Kidney Diseases*, 24(2), 235-246.

Lok, P. (1996). Stressors, coping mechanisms and quality of life among dialysis patients in Australia. *Journal of Advanced Nursing*, 23(5), 873-881.

Lohr, K. N., & Schroeder, S. A. (1990). A strategy for quality assurance in Medicare. *New England Journal of Medicine*, 322(10), 707-712.

Lowrie, E. G. (1994). Chronic dialysis treatment: Clinical outcome and related processes of care. *American Journal of Kidney Diseases*, 24(2), 255-266.

Lowrie, E. G., Laird, N. M., Parker, T. F., & Sargent, J. A. (1981). Effect of the hemodialysis prescription of patient morbidity: report from the National Cooperative Dialysis Study. *New England Journal of Medicine*, 305(20), 1176-1181.

Lowrie, E. G. & Lew, N. L. (1990). Death risk in HD patients: Predictive value of commonly measured variables and evaluation of death rate differences between facilities. *American Journal of Kidney Diseases*, 15 (5), 458-482.

Marr, J., & Greengarten, M. (1995). Patient satisfaction: A customer service approach. *Healthcare Management Forum*, 8(3), 52-56.

Mathieson, C. M., & Stam, H. J. (1995). Renegotiating identity: cancer

narratives. *Sociology of Health and Illness*, 17(3), 283-306.

Mattern, W. D., Hak, L. J., Lamanna, R. W., & Teasley, K. M. (1982). Malnutrition, altered immune function and the risk of infection in maintenance HD patients. *American Journal of Kidney Diseases*, 1, 206-218.

Meyer, K. B. (1995). The outcomes of ESRD and its treatment. [Review]. *Advances in Renal Replacement Therapy*, 2(2), 101-111.

Molzahn, A. (1991). The reported quality of life of selected home hemodialysis patients. *American Nephrology Nurses Association Journal*, 18(2), 173-180, 194.

Montemuro, M., Martin, L. S., Jakobson, S., Mohide, E. A., Beecroft, M. L., Porterfield, P., & Ollinger, D. (1994). Participatory control in chronic hospital-based hemodialysis patients. *American Nephrology Nurses Association Journal*, 21(7), 429-438.

Morse, J. M., & Johnson, J. J. (1991). Toward a theory of illness: The illness-constellation model. In J.M.A. Morse and J.L. Johnson (Eds.), *The Illness Experience: Dimensions of Suffering*. Newbury Park: Sage Publications.

Morse, J. M., & Field, P. A. (1996). *Nursing Research: The application of qualitative approaches*. London: Chapman & Hall.

Norman, I. J., Redfern, S. J., Tomalin, D. A., & Oliver, S. (1992). Developing Flanagan's critical incident technique to elicit indicators of high and low nursing care from patients and their nurses. *Journal of Advanced Nursing*, 17(5), 590-600.

Oberley, E. T. (1991a). A patient review of the ESRD program: Part 1. *Nephrology News & Issues*, 5(4), 22-26.

Oberley, E. T. (1991b). A patient review of the ESRD program: Part 11. *Nephrology News & Issues*, 5(5), 18-24.

O'Brien, M. E. (1980). Hemodialysis regimen: Compliance and social environment: A panel analysis. *Nursing Research*, 29(4), 251-255.

O'Brien, M. E. (1983). *The courage to survive: The life career of the chronic dialysis patient*. New York: Grune & Stratton.

O'Brien, M. E. (1990). Compliance behavior and long-term maintenance dialysis. *American Journal of Kidney Diseases*, 15 (3), 209-214.

Owen, S. R., Lew, N. L., Yan, Liu S. M., Lowrie, E. G., & Lazarus, J. M. (1993). The urea reduction ratio and serum albumin concentrations as predictors of mortality in patients undergoing hemodialysis. *New England Journal of Medicine*, 329(14), 1001-1006.

Paget, L., & Tarlov, A. R. (1996). The Medical Outcomes Trust: Improving medical outcomes from the patient's point of view. *The Journal of Outcomes Management*, 3 (3), 18-23.

Parkerson, G. R., Jr., Broadhead, W. E., & Tse C. K. (1993). The Duke Severity of Illness Checklist (DUSOI) for measurement of severity and comorbidity. *Journal of Clinical Epidemiology*, 46 (4), 379-393.

Parfrey, P. S., Foley, R. N., Harnett, J. D., Kent, G. M., Murray, D. C., & Barre, P. E. (1996a). Outcomes and risk factors of ischemic heart disease in chronic uremia. *Kidney International*, 49(5), 1429-1434.

Parfrey, P. S., Foley, R. N., Harnett, J. D., Kent, G. M., Murray, D. C., & Barre, P. E. (1996b). Outcomes and risk factors for left ventricular disorders in chronic uremia. *Nephrology, Dialysis, and Transplantation*, 11(7), 1277-1285.

Parfrey, P. S., Vavasour, H., Bullock, M., Henry, S., Harnett, J. D., & Gault, M.H. (1989). Development of a health questionnaire specific for end-stage renal disease. *Nephron*, 52(1), 20-28.

Peters, D. A. (1991). Measuring quality: inspection or opportunity? *Holistic Nursing Practice*, 5(3), 1-7.

Peters, D. A. (1995). Outcomes: The mainstay of a framework for quality care. *Journal of Nursing Care Quality*, 10(1), 61-69.

Pettit, L. S., & White, C. L. (1991). Providers' and consumers' perceptions of quality health care. *Journal of Nursing Staff Development*, 7(1), 5-9.

Pontin, D. J. T., & Webb, C. (1996). Assessing patient satisfaction. Part 2. Findings: Nursing, the hospital and patients' concerns. *Journal of Clinical Nursing*, 5(1), 33-40.

- Reiss, D., Gonzalez S., & Kramer, N. (1986). Family process, chronic illness and death: On the weakness of strong bonds. *Archives of General Psychiatry*, 43(8), 795-804.
- Rempusheski, V. F., Chamberlain, S. L., Picard, H. B., Ruzanski, J., & Collier, M. (1988). Expected and received care: Patient perceptions. *Nursing Administration Quarterly*, 12(3), 42-50.
- Reuben, D. A., Rubenstein, L. V., Hirsch, S. H., & Hays, R. D. (1992). Value of functional status as a predictor of mortality: Results of a prospective study. *American Journal of Medicine*, 93(6), 663-669.
- Rittman, M., Northsea, C., Hausauer, N., Green C., & Swanson, L. (1993). Living with renal failure. *American Nephrology Nurses Association Journal*, 20(3), 327-331.
- Ritz, E., & Koch, M. (1993). Morbidity and mortality due to hypertension in patients with renal failure. *American Journal of Kidney Diseases*, 21(5 Suppl. 2), 113-118.
- Robinson, C. A. (1993). Managing life with a chronic condition: The story of normalization. *Qualitative Health Research*, 3(1), 6-28.
- Rodriguez, R. A. (1997). Use of the medical differential diagnosis to achieve optimal end-stage renal disease outcomes. *Advances in Renal Replacement Therapy*, 4(2), 97-111.
- Siegal, B. R., Calsyn, R. J., & Cuddihee, R. M. (1987). The relationship of social support to psychological adjustment in end-stage renal disease. *Journal of Chronic Diseases*, 40(4), 337-344.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- Sawatzky, J. E., & MacDonald, M. A. (1994). Challenges to achieving quality care: Efficiency, effectiveness and beneficence. *International Nursing Review*, 41(1), 22, 27-31.
- Tarlov, A. R., Ware, J. E., Jr., Greenfield, S., Nelson, E. C., Perrin, E., & Zubkoff, M. (1989). The Medical Outcomes Study: An application of methods for monitoring the results of medical care. *Journal of the American Medical*

Association , 262(7), 925-930.

Taylor, C. (1995). Rethinking nursing's basic competencies. *Journal of Nursing Care Quality*, 9(4), 1-13.

Tell, G. S., Schumaker, S. A., Mittelmark M. B., Russell, G., Hylander B., & Burkart, J. A. (1995). Social support and health-related quality of life in Black and White dialysis patients. *American Nephrology Nurses Association Journal*, 22(3), 301-308.

U. S. Renal Data Systems 1992 Annual Report. IV. Comorbid conditions and correlations among 3,399 incident hemodialysis patients. *American Journal of Kidney Diseases*, 20(Suppl. 2), 32-38.

Van Valkenberg, D., & Snyder, S. (1994). Challenges and barriers to managing quality in an end-stage renal disease facility. *American Journal of Kidney Diseases*, 24(2), 337-345.

Vuori, H. (1987). Patient satisfaction - An attribute or indicator of the quality of care? *Quality Review Bulletin*, 13(3), 106-108.

Vuori, H. (1991). Patient satisfaction - does it matter? *Quality Assurance Health Care*, 3(3), 183-189.

Ware, J. E., Jr., & Sherbourne C. D. (1992). The MOS 36-item Short-Form Health Survey (SF-36): I. Conceptual framework and Item selection. *Medical Care*, 30(6), 473-483.

Wilde, B., Starrin, B., Larsson, G., & Larsson, M. (1993). Quality of care from the patient perspective: A grounded theory study. *Scandinavian Journal of Caring Science*, 7(2), 113-120.

Williams, B. (1994). Patient satisfaction: A valid concept? *Social Science and Medicine*, 38(4), 509-516.

Woodyard, L. W. & Sheetz, J. E. (1993). Critical pathway patient outcomes: The missing standard. *Journal of Nursing Care Quality*, 8(1), 51-57.

Young, W. B., Minnick, A. F., & Marcantonio, R. (1996). How wide is the gap in defining quality care? Comparisons of patient and nurse perceptions of important aspects of patient care. *Journal of Nursing Administration* , 26(5), 15-20.

Appendix A
Consent Form

Faculty of Medicine, Memorial University of Newfoundland,
St. John's, Newfoundland A1B 3V6

CONSENT TO PARTICIPATE IN HEALTH CARE RESEARCH

TITLE: The Quality of Hemodialysis Care from the Patients' Perspective:
An Interactive Point of View

INVESTIGATOR: Dr. Christine Way
Telephone: 737-6872/6695

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your normal treatment.

Confidentiality of information concerning participants will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Physicians and nurses involved with your care will not have access to your taped interviews or any other information that could potentially identify you as the source.

Purpose of the Study: You are being asked to participate in a research study of patients receiving hemodialysis treatment. Although many patients receive this type of treatment, very little is known about what the experience is really like for them. The purpose of this study is to explore patients' perceptions of hemodialysis care, and to identify what aspects of that care is most and least valued.

Description of Procedures and Tests: You are being asked to participate in two interviews which will be conducted at a place and time that is convenient for you. Interviews will be audiotaped (with your permission). The tape will be used solely to assist the interviewer in remembering the details of your conversation, and will be made available only to the principal investigator of the study.

During the first interview you will be asked to reflect upon and describe your experience with hemodialysis treatment. You will be asked to think about an experience that left a lasting impression, and share any thoughts, perceptions and feelings that you remember about it. In addition you will be asked to comment on your overall satisfaction with the care that you receive, and possible areas that you would like to see improved.

At approximately one to two months following the first interview, you will be contacted for a second interview. At this time you will be asked to read a summary of the initial interview, confirm whether it accurately reflects your experience with hemodialysis treatment, and rate which aspects of the experience are most important to you. You will also be given an opportunity to provide any additional information.

Duration of Participation: The first interview will take approximately 60 to 90 minutes, and the second approximately 30 minutes. Both interviews will be completed within two months.

Foreseeable Risks, Discomforts or Inconveniences: There are no expected risks from participating in this study. You may refuse to answer any questions which make you feel uncomfortable, and terminate the interview at any time. All information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the principal investigator and interviewers. Your name will not appear on the audiotape or written copy, and any names that you might mention during the course of the interview will be removed from the transcribed texts.

Benefits: You may not derive any direct benefits from participating in this study. However, the information that you provide may help nurses and physicians plan more appropriate care for you and others receiving hemodialysis treatment.

Other Information: Findings of this study will be available to you and health care professionals upon request. Findings may be published but you will not be identified. The investigator will be available during the study at all times should you have any questions or concerns about your continued participation.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I, _____, the undersigned, agree to my participation in the research study described.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

Signature of Participant Date

Signature of Witness Date

I, _____, the undersigned, agree to be audiotaped during each interview.

Signature of Participant Date

Signature of Witness Date

To the best of my ability, I have fully explained the nature of this study to the participant. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

Signature of Interviewer Date

Phone Number

Appendix B

Personal Data Retrieval Questionnaire

PERSONAL DATA RETRIEVAL QUESTIONNAIRE

Patient's name: _____

Id #: _____

Gender: M ___ F ___

Date of birth: _____

(d/m/yr)

Marital Status: _____

Occupation: _____ Employed: Yes ___ No ___

Place of Residence: _____

Commuting Distance for Treatment: _____

Start Date of Hemodialysis: _____

Length of time on dialysis: _____

Date 1st approached by Nurse Manager: _____

Date approached by researcher: _____

Audio Taped Interviews

Date of 1st interview: _____ Length of interview: _____

Date submitted for transcription: _____

Date returned for proof-reading : _____

Date of 1st interview: _____ Length of interview: _____

Date submitted for transcription: _____

Date returned for proof-reading : _____

Appendix C
Interview Schedule

Interview Script

I am interested in your experiences with hemodialysis care from when you first started treatment up to now. You have probably had some interesting experiences during this time. I would like for you to take some time to reflect upon these experiences and tell me in your own words what dialysis care means for you. Feel free to talk about whatever comes to mind.

Examples of Probes/Questions to Facilitate the Interview

1. Could you think about your most recent dialysis treatment and describe what you experienced before, during and after the treatment?
2. Thinking back to your initial treatments and what it was like for you then, could you describe any memorable events that may have left a lasting impression with you?
3. We all have good days and bad days. Could you reflect upon your experiences with dialysis and talk about what makes the treatment experience a good or bad one?
4. How do you feel about being on dialysis? What are some of the positive aspects? Negative aspects?
5. Can you recall a significant personal experience that left a lasting impression in your memory? If so, when and how did this experience occur? How important was it for you at the time? Do you believe that it is still important?
6. How would you rate the overall care that you receive while on dialysis? What would make the care better? Are there particular aspects of your care that could be improved? (Specific areas to probe, if not mentioned: physical aspects - pain, discomfort; practical aspects - travel time, time loss from work, weekend appointments; interpersonal relations with clinic staff).
7. Are there any other comments or thoughts that you would like to share

with me about your experiences while receiving dialysis treatment?

The following questions were added to the original interview schedule as the number of interviews increased and new areas requiring exploration were identified by the participants.

8. How long was it before you felt comfortable with the routine of dialysis?
9. Are you attentive to the different times that procedures are carried out during dialysis?
10. How would you compare the nurses and doctors in terms of their attentiveness?
11. Were you presented with choices regarding home dialysis versus in-center dialysis?
12. Were you followed through a pre-dialysis clinic or did you start dialysis as a direct admission?
13. Could you talk a little about the support you have received since starting dialysis (i.e., family, friends, social worker, dietitian, nurses, doctors, Kidney Foundation and/or other agencies)?
14. Hypothetical situation: If I were a patient coming to talk to you before going on dialysis, what would could you tell me to help me prepare for this treatment?

Appendix D

Letter of Approval from the Human Investigation Committee



Memorial

University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

16 April 1996

TO: Dr. Christine Way

FROM: Dr. Verna M. Skanes, Assistant Dean
Research & Graduate Studies (Medicine)

SUBJECT: Application to the Human Investigation Committee - #96.45

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled **"The Quality of Hemodialysis Care from the Patients' Perspective: An Interactive Point of View"**.

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

It will be your responsibility to seek necessary approval from the hospital(s) wherein the investigation will be conducted.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

Verna M. Skanes, Ph.D.
Assistant Dean

cc Dr. K.M.W. Keough, Vice-President (Research)
Dr. Ford Bursey, General Hospital Representative, HIC
Dr. Eric Parsons, Medical Director, General Hospital

Appendix E

Letter of Approval from the Health Care Corporation



May 15, 1996

TO: Dr. Christine Way
FROM: Eric R. Parsons, MD,CCFP
SUBJECT: Research Proposal

Your research proposal - HIC # 96.45 - "The Quality of Hemodialysis Care From The Patients' Perspective: An Interactive Point of View" has been considered by the Research Proposal Approval Committee (RPAC) of the Health Care Corporation of St. John's at their most recent meeting.

The committee has approved your proposal to be conducted at the General Hospital Site within the Health Care Corporation of St. John's. This approval is contingent on the appropriate funding being provided and continued throughout the project and on the provision of regular progress reports as least annually to the RPAC Committee.

Eric R. Parsons, MD,CCFP
Vice-President, Medical Services

ERP'ek
cc: Linda Purchase, Research Centre
Site Administrator, General Hospital

147

General Hospital

Health Sciences Centre, 300 Prince Philip Drive, St. John's, Newfoundland, Canada A1B 3V6 Tel: (709)737-6300 Fax: (709)737-6400

SITES: General Hospital • James' Child Health Centre/ Children's Rehabilitation Centre • Leonard A. Miller Centre
St. Clare's Mercy Hospital • Salvation Army Grace General Hospital • Dr. Walter Templeman Health Centre • Waterford Hospital

Appendix F

Tables of Major Categories, Properties and their Descriptors

The tables contain the properties and descriptors for each of the theoretical constructs. The number of participants identifying each indicator defining the descriptors of the various properties of the major categories is indicated as (n). This refers to the number of participants who identified the indicator at least once during the interview process. Although not depicted in the table, the vast majority of participants identified at least one descriptor defining the key properties.

Table 3
Redefining the Self (N = 36)

Properties & Descriptors	n	%
I. Health: Emotional & Psychological Functioning		
Dealing with uncertainty		
- emotional turmoil	24	66.7
- psychological/emotional adjustments	33	91.7
Emotional struggles/dilemmas		
- positive/negative attitude	28	77.8
- resisting/accepting treatment restrictions	30	83.3
- uncertainty of treatment effects on health & quality of life	22	61.1
II. Adapting to a New Normal		
Emotional/psychological adjustment to treatment		
- comfort with illness chronicity	21	58.3
- acceptance/rejection of dialysis treatment routine	32	88.9
- relaxing/not relaxing during dialysis/non-dialysis days	36	100.0
- more comfortable with treatment effects	34	94.4
- adjustment/resistance to lifestyle restrictions	33	91.7
Assuming the burden of decision making		
- accepting body readiness/choosing treatment options	33	91.7
- implementing control measures	25	69.4
- assuming responsibility for self-care	26	72.2
- weighing the odds	23	61.1

Table 4
Quality of Supports (N = 36)

Properties & Descriptors	n	%
I. Informal Support Roles		
Supportive role of significant others		
- maintaining relationships	33	91.7
- providing assistance	32	88.9
- adapting to a reduced lifestyle	23	63.9
- coping with the magnitude of illness	25	69.4
- buffering emotional impact	11	30.6
- protection from burden of care	20	55.6
Interactions with fellow patients		
- family-like atmosphere	22	61.1
- comfort & support	24	66.7
- impact of acute illness of others	25	69.4
- losses (death of fellow patients)	17	47.2
II. Nursing Care Effectiveness		
Barriers to quality of nursing care		
- heavy workload & staffing levels	31	86.1
- non-conducive work environment	24	66.7
Nurses' levels of expertise		
- skills and clinical judgements	32	88.9
- degree of attentiveness	33	91.7
Emotional/psychological adjustment strategies		
- acceptance as a person	24	66.7
- attitude	33	91.7
- promotes understanding & acceptance	30	83.3
- provides comfort measures	27	75.0

III. Medical Care Effectiveness

Barriers to quality medical care		
- restricted availability & rotation schedules	15	41.7
Physicians levels of expertise		
- skills & clinical judgement	32	88.9
- degree of attentiveness	28	77.8
Emotional/psychological adjustment strategies		
- attitude	31	86.1
- promotes understanding and acceptance	34	94.4

Table 5**Meanings of Illness and Treatment (N = 36)**

Properties & Descriptors	n	%
I. Appraisal of Disease		
Precipitating factors	28	77.8
Interactive effects with comorbid diseases	25	69.4
Unpredictable illness effects	25	69.4
II. Appraisal of Treatment		
Knowing prescribed regimen and why needed		
- assimilating information on treatment	31	86.1
- importance of treatment protocols	23	63.9
- short/long term treatment benefits/complications	29	80.6
Impact on overall health and well-being		
- physical functioning level (during dialysis)	34	94.4
- physical functioning level (after dialysis)	34	94.4
- lifeline & quality of life	24	66.7
III. Ambivalence: Knowing versus Doing		
Forces/barriers to acceptance: attentive to		
- treatment protocols	35	97.2
- changes in treatment protocols	34	94.4
- technical & physiological problems	34	94.4
Forces/barriers to acceptance: information seeking regarding		
- change in health status	29	80.6
- treatment errors	9	25.0
Illness precipitating dialysis		
- seeking attention	29	80.6
- seeking information regarding		
- changes in health status	11	30.6

