

University of Montana

ScholarWorks at University of Montana

Graduate Student Theses, Dissertations, &
Professional Papers

Graduate School

2012

Subjective Quality of Life in Dialysis Patients

Cindy Schaumberg

The University of Montana

Follow this and additional works at: <https://scholarworks.umt.edu/etd>

Let us know how access to this document benefits you.

Recommended Citation

Schaumberg, Cindy, "Subjective Quality of Life in Dialysis Patients" (2012). *Graduate Student Theses, Dissertations, & Professional Papers*. 929.

<https://scholarworks.umt.edu/etd/929>

This Dissertation is brought to you for free and open access by the Graduate School at ScholarWorks at University of Montana. It has been accepted for inclusion in Graduate Student Theses, Dissertations, & Professional Papers by an authorized administrator of ScholarWorks at University of Montana. For more information, please contact scholarworks@mso.umt.edu.

SUBJECTIVE QUALITY OF LIFE IN DIALYSIS DEPENDENT END STAGE

RENAL DISEASE PATIENT

By

CINDY ANDERSON SCHAUMBERG, LCSW

Masters of Social Work, Eastern Washington University, Cheney, Washington, 1993

Bachelors of Arts, Idaho State University, Pocatello, Idaho, 1972

Dissertation

presented in partial fulfillment of the requirements
for the degree of

IIP Ph.D.

The University of Montana

Missoula, MT

May 2012

Approved by:

Sandy Ross, Associate Dean of The Graduate School
Graduate School

Ann Cook, Ph.D., Chair
Psychology

Teresa Sobieszczyk, Ph.D.
Sociology

Jean T. Carter, Pharm.D., Ph.D.
Pharmacy

Annie Sondag, Ph.D.
Health & Human Performance

J.D.A. Lakatua, M.D.
St. Patrick Hospital

COPYRIGHT NOTICE TEMPLATE

© COPYRIGHT

by

Cindy Anderson Schaumberg
2012

All Rights Reserved

Schaumberg, Cindy, Ph.D., May 2012

IIP

Quality of Life in Hemodialysis Patients

Chairperson: Ann Cook, Ph.D.

With the ever increasing ability of medical technology to prolong life, quality of life is an increasingly legitimate medical outcome. This is an ethnographic study on the perceived quality of life of hemodialysis dependent end stage renal disease patients. The study used participant observations and in-depth patient interviews to elicit the perspective of hemodialysis dependent end stage renal disease patients. Findings addressed the utility of dialysis for patients of, patient values leading to renal replacement therapy, and issues that might make patients perceive treatment as futile.

Acknowledgments

I would not have completed this doctoral program without the support of many fantastic people. I have had a wonderful doctoral committee. Ann Cook was my chair person and supported me through five long years. She was always there for me especially during a rough summer of self reflection when the honesty of study respondents left me humbled. Thank you, Ann. Teresa Sobieszczyk always kept my eyes on true north. Thank you, Teresa. Thanks to Jean Carter who showed me the beauty of quantitative research and shared a value of learning for learning's sake. Annie Sondag, thank you for your guidance in never forgetting the big picture. Tony Lakatua brings life to the word courage. He has always been and continues to be one of my heroes.

It goes without saying that I am thankful for my wonderful husband. He has been a true partner for all the years of our life together. Our daughters have cheered me on through this whole process. Their support has been terrific. Many thanks go to my friends and colleagues. You have been great.

Finally, I would like to express my unending gratitude to the patients who shared their lives with me for this study. Your courage, grace, and generosity are unmatched. I will never be able to thank you enough!

Table of Contents

Chapter One	2
Introduction	2
Dissertation Organization	3
Research Questions	3
Significance of the Study	3
Background of this Study	4
Basic Principles of End Stage Renal Disease and Dialysis	4
Kidney Function	5
Societal Involvement in Dialysis	7
Adjustment to Hemodialysis	9
<u>Hemodialysis Demands</u>	10
Quality of Life	11
Quality of Life as an Outcome Measure for Medicine	12
Treatment Futility	14
Ethics of Medical Futility	15
Obligation to Assess the Quality of Life in Health Care	18
The Practical Utility of Information	18
A Self-Determined Quality of Life Assessment	20
Ways of Understanding: The Dimensions of Health Outcomes	25
Productivity Outcomes	26
Cultural Relativism	29
Summary	30
Chapter Two	32
Introduction	32
Coping and Social Support	33
Giving Support	389
Social Construction of Support	40
Social Constructionism as a Research Paradigm	41
Physician and Patient Relationship	44
World Views	45
Chapter Three	47
Introduction	47
Definition of Terms	47
Delimitations	47
Limitations	48
Overview of the Research Approach	48
Interpretative and Social Work Paradigms: Their Intersection in Chronic Illness Research	
Interviewing	50
Participants	54
Research Instruments	56
Informed Consent	56
Role of Researcher	56
Participant Observation	58

	vi
Interviews	59
Procedures for Analysis Coding and Memoing	62
Mapping	64
Measures to Enhance Data Quality, Trustworthiness, and Applicability	64
Summary	66
Chapter Four	67
Research Results	67
Contextual Factors	67
Study Setting—Dialysis Unit	68
Study Setting—City and State	68
Study Setting—Catholic Hospital	69
Economic Factors	69
Oversight	70
Patient-Physician Relationship	70
Illness Community Support Utilization Benefits	71
Physical Context of Dialysis	72
Foreseeable Consequences	77
Participant Demographics	78
Spousal Support	79
Age	81
Treatment Costs	81
Co-Morbid Illness and Derivative Conditions	82
Quality of Life	83
Emotional Deterioration in Quality of Life	84
Do or Die	85
Empathy	87
Compassion	87
Family Ties	88
Spiritual Support	886
Support Provided within the Illness Community	90
Physical Deterioration of Quality of Life	90
Accepting Chronic Dialysis	91
Loss of Freedom	92
Concerns About Funding	92
Perceived Resilience	93
Patient and Health Care Providers	94
Summary	97
Chapter Five	98
Discussion and Conclusions	98
Introduction	98
Recommendations for Practitioners	104
Recommendations for Further Research	1025

There are things that we don't want to happen
but have to accept, things we don't want to know
but have to learn, and people we can't live without but
have to let go.

Author Unknown

Quote brought to the researcher by one of the patient-participants.

Chapter One

Introduction

Within the United States and other more industrialized countries, with the ever increasing ability to prolong life, the patient's quality of life has become an increasingly legitimate medical outcome. Greater understanding now exists that health outcomes defined only in terms of mortality and morbidity risk a substantial loss of vital patient information. Multidimensional conceptualizations of health include both functional and subjective perceptions of illness and well-being. Patients' lived experience of what truly constitutes a quality life becomes paramount (Ware, 1987). Medical providers increasingly consider patient quality of life when making treatment decisions with patients. Policy makers include expected quality of life when making funding decisions for local hospitals, state human services, and federal level agencies such as Medicare. Not including assessment of quality of life requires clinical justification for medical practice and research boards. Even when cure is impossible, quality of life becomes a valid endpoint of medical efforts in the treatment of chronic disease.

This is a study utilizing ethnographic techniques within a constructivist paradigm designed to explore the perceived quality-of-life of end stage renal disease patients. This study approach can provide a way to explore and generate ideas and theory. Interviews elicit and reflect the rich, in-depth perspective of patients who are dependent on lifelong hemodialysis. Constructionist theory applied to subjectively defined dimensions of patient quality of life can provide rich, clinically important information to inform

decision-making for a wide spectrum of health care professionals and for patients themselves.

Dissertation Organization

This section discusses questions guiding the research. It also contains a short definition of terms for this project, study delimitations, limitations, and a statement of the significance of this research. Following sections contain an overview of literature areas pertinent to the research, research methodology, study results and analysis of the data, and study conclusions. Appendices and a bibliography for this study follow.

Research Questions

The research questions for this study will be:

1. What utility does life hold for end stage renal disease patients?
2. What values are involved in the decision to pursue treatment when a cure is not possible?
3. What is lost in life to make further treatment futile from a patient perspective?

Significance of the Study

There is something important to be understood about patient choice of treatments when faced with incurable disease. As the seeming miracles of modern science give us the means for a long life, patients and providers alike are faced with the question of how to understand and predict the quality of that life. The end stage renal disease patients in this study can help us understand the lived experience of life with chronic disease. What utility does life hold for these patients? What values are involved in the decision to pursue treatment when a cure is not possible? What is lost in life to make further

treatment futile in the patient's estimation? Understandings gained in this study can help providers and patients set care goals and match them with treatment choices. Better understanding of factors contributing to patient perception of quality of life can provide vital insight to health care providers, advance medical knowledge, assist in developing social policy, and contribute to public and private decision-making. Potential audiences for this study are patients, physicians, nurses, social workers, policymakers, and funding sources for research and dialysis treatments.

This study uses in depth interviews and participant observation. The goal of this study is to help illuminate the knowledge, beliefs, values, meanings, and attitudes contributing to patient perception of quality of life. This project contributes to a greater understanding of patient views regarding their integrity, independence, autonomy, and continuing contribution to the quality of life of others. The study may assist health care providers, family, program evaluators, and health care policymakers better understand patients' subjective evaluation of quality of life.

Background of this Study

Basic Principles of End Stage Renal Disease and Dialysis. End stage renal disease (ESRD) is the terminal and final phase of loss of renal (kidney) function which can be acute or represent a progressive decline of many years. End stage renal disease is diagnosed when chronic renal replacement therapy is necessary due to the severity of symptoms and is necessary for the patient to survive. The clinical picture of ESRD is complicated and its etiology includes a variety of diseases, i.e. diabetes, hypertension, genetically-based diseases, sclerotic disease, thrombotic injury, cancer, and toxic insults to the kidney, among others. Patients with end stage renal disease have major organ

failure which cannot be cured but can be treated with renal replacement therapy, dialysis, or kidney transplantation. Kidney failure can result in a symptom complex which may involve every major body system. (Gutch, Stoner, and Corea, 1993)

Kidney Function. Cellular activity metabolizes nutrients and produces oxygen, protein and other wastes. Plasma in the blood provides a medium for these complex cellular chemical processes that produce energy for heat, motion, and cell regeneration. Normally functioning kidneys control this balance of fluids and chemical substances. This homeostasis is regulated through the kidney's excretion or conservation of fluid and removal of metabolic waste as needed. The kidneys also serve endocrine functions including the production of renin and angiotensin, which affect sodium, fluid volume, and blood pressure; as well as the production of erythropoietin, controlling red cell production in the bone marrow; and prostaglandins. (Gutch, Stoner, and Corea, 1993)

Treatment. Treatment of renal failure most commonly involves maintenance dialysis, a form of chronic mechanical life support which replaces organ function. Treatment is accomplished by cleansing blood and removing excess fluid with a hemodialysis machine. Blood is removed and returned via a catheter, fistula, or graft access surgically placed primarily in the patient's arm or chest, although other sites can be used if these sites are not viable.

The concept of hemodialysis was first developed in the 1860's by Graham to describe his process of selective diffusion. Abel, Rountree, and Turner devised an apparatus for blood dialysis in 1913. They called their process vividiffusion and used their artificial kidney to treat uremic animals. Kolff and Berk, in 1943, developed the first clinically successful hemodialyzer. The first disposable dialyzer was a Travenol twin

coil dialyzer commercially marketed in 1956, and in 1965 hollow fiber artificial kidneys were developed in the United States. Hollow-fiber artificial kidneys are the most commonly utilized type of dialyzer today. (Gutch, Stoner, and Corea, 1993)

The term hemodialysis is derived from the term “hemo” for blood and “dialysis” indicating filtration. Toxins are filtered during the blood exchanges by semipermeable membranes and disposed of by the dialysis fluid. Dialysis fluid is an electrolyte solution with a composition very similar to that of normal plasma. In hemodialysis, the patient’s blood passes through a compartment formed by a semipermeable membrane surrounded by dialysis fluid. Most plasma proteins, red cells, white cells, and platelets are too large to pass through the membrane. Smaller particles, for example urea, creatinine, and glucose, can cross the dialysis membrane easily and so can be filtered out and removed. This diffusion of differing sized particles across a semipermeable membrane is the basic process of dialysis. The dialyzer, a type of artificial kidney, removes uremic toxins, corrects acid-base disturbances, and restores electrolyte balances. Controlled fluid removal during dialysis, compensating for fluid retention from renal failure, is termed ultrafiltration. (Gutch, Stoner, and Corea, 1993).

Most end stage renal disease patients receive dialysis treatments three times a week for an average of four hours each treatment. Frequent hemodialysis reduces the interval for accumulation of wastes and fluids. Continuous treatment would most closely mimic the natural function of kidneys. The duration and frequency of most dialysis prescriptions is a compromise between optimal patient health and the practical costs of dialysis in supplies and time. The goal of dialysis is to balance the safest and most

comfortable treatment for the patient while maximizing efficacy. (Gutch, Stoner, and Corea, 1993)

Health complications can occur during dialysis, primarily as a result of fluid and chemical shifts from the cellular and vascular systems. Complications can include headaches, weakness, nausea, cramping, hypotension, and infections at the access site. More troublesome health complications are attributable to end stage renal disease itself. Anemia, renal osteodystrophy, metastatic calcification in soft tissue, uremic neuropathy, and sexual/reproductive problems all increase as renal failure progresses and cannot be fully addressed through hemodialysis treatments. (Gutch, Stoner, Corea, 1993)

Societal Involvement in Dialysis. In 1973 the United States Congress passed the Medicare End Stage Renal Disease Program and as a result hemodialysis took on larger social implications. This change in Medicare law made end stage renal disease the only catastrophic illness whose treatment, dialysis and transplantation, financially supported with public dollars based on the sole criteria of the disease rather than financial need, age, or disability. Federally supported treatment of end stage renal disease was declared the right of all persons with kidney failure. Medicare pays for roughly 80% of the costs of treatment. (Congressional Federal Register, 2008) The Veterans Health Administration pays for dialysis as a military-related benefit. (Veterans Health Administration Eligibility Criteria. 2011) Inclusion in Medicare does allow private insurance to exclude ESRD patients from supplemental insurance policies so many patients struggle to afford the 20% of treatment costs not covered by Medicare. (Edgell, et. al, 1996)

This financial commitment through Medicare gives society a significant stake renal replacement therapy which can be life extending but currently offers no cure. Quality of life and how to measure it has become a vital part of policy and decision-making regarding resource allocation. Good decision-making requires a reliable method of measuring impact on patients' quality of life. An optimal quality of life measurement captures the impact of disease, injury, and/or treatment on the physical, mental, and social dimensions of well-being (Edgell, et al., 1996).

The psychosocial aspects of dialysis therapy can impede or support patient adjustment to the stressors and demands of end stage renal disease and its treatment. Medicare Conditions of Participation require that when patients initiate dialysis a clinical

social worker conducts an in-depth psychosocial assessment. This assessment involves the patient, and with the patient's permission, his or her family. The psychosocial assessment is presented to an interdisciplinary treatment team composed of the patient, nephrologist, registered nurse, dietician, and clinical social worker. Composition of this interdisciplinary team is mandated by Medicare Conditions of Coverage. Inclusion of a Master's in Social Work (MSW) prepared clinical social worker acknowledges the specialized clinical training of an MSW and that individual's value to dialysis patients in psychological and social aspects of adjustment to financial concerns, changes in the ability to work, changes in social relationships, family stress, role changes, and living with a life threatening chronic disease. (Gutch, Stoner, and Corea, 1993)

Adjustment to Hemodialysis. Researchers and health care providers generally accept three periods of adjustment to dialysis: the honeymoon period, the disenchantment and discouragement period; and long-term adaptation. There is not always a predictable progression through each phase. Patients may experience each phase for differing periods of time and may cycle back through some phases particularly when complications of ESRD or other disease processes become manifest. (Goodheart & Lansing, 1996; Gutch, et al, 1993)

The honeymoon period is defined as a patient's initial reaction to initiation of dialysis as a treatment for otherwise fatal kidney failure. The alleviation of physical and psychological symptoms of uremia is often accompanied by feelings of hope and confidence that there is a future. Both patients and their families often experience a relief that coping with this life-threatening health crisis is possible. This almost euphoric state

of relief can be expected to last from three months to a year. (Goodheart & Lansing, 1996; Gutch, et al 1993)

Following this very positive period is a period of disenchantment and discouragement and decreased feelings of positivity and hope. Both family and patient begin to experience the constraints imposed by dialysis on activities, diet, time, and money. Emotions typically turn from gratefulness and confidence to sadness and hopelessness. Anxiety and depression, which were interwoven with positive affects during the honeymoon phase, become more dominant emotions. (Goodheart & Lansing, 1996)

Long-term adaptation to the chronicity of end stage renal disease usually begins from twelve to eighteen months after the initiation of dialysis therapy. During this phase, the patient and his or her family experience the challenges inherent in living with a chronic disease. Some acceptance and accommodation is made to the limitations and complications of ESRD and dialysis. Restrictions in the patient's diet, activities, lifestyle, as well as the sheer commitment of time to dialysis procedures, become incorporated into this new health normal. Although this period can be characterized as smoother than previous phases, the patient often cycles through depression and anxiety brought on by internal and external threats to emotional homeostasis. Patients are faced with what may be permanent demands and stresses of themselves and their families: changes in family relationships and roles; changes in sexual functioning brought on by fluid restrictions and medications; threats to jobs or educational goals; feelings of guilt and loss; dependence on medical staff; loss of independence; feelings of worthlessness; and an understanding that without this treatment, death is the predictable outcome.

Social support, particularly family support, helps with positive patient adjustment during this chronic stage. (Goodheart & Lansing, 1996; Gutch, Stoner, and Corea, 1993)

Hemodialysis Demands. Hemodialysis demands tremendous commitment on behalf of the patient and family. It requires machine dependent renal replacement for an average of four hours three times per week. In addition, many patients find that adherence to fluid and diet restrictions is rigorous and difficult. Fluid gains between dialysis treatments are restricted to four percent of body weight (about one liter for an averagely sized adult). A renal diet restricts any food containing high levels of phosphorus, sodium, or potassium is restricted in a renal diet. Consumption of fruits, nuts, milk, cheeses, and processed foods is limited. The time demanded by thrice weekly dialysis treatments often interferes with the daily life of patients and care givers. Dialysis units are often geographically distant requiring patient travel for long distances and extended times. Fistula or graft access involves often painful needle punctures with each treatment using 16-14 gage needles large enough to accommodate dialysis pressures. Yet despite these problems, the reality is that dialysis is the only way for end stage renal disease patients to stay alive. (Gutch, Stoner, and Corea, 1993)

Quality of Life. Quality of life encompasses all physical, psychological, and social aspects of patient life. Since these are inherently relative perceptions for each patient, assessing quality of life “must take into account the significance of these highly subjective perceptions”. (Gutch et al., 1993, 242) The history of quality of life as an individual and social construct begins with Aristotle. In his Nichomachean Ethics, Aristotle referred to the satisfaction, happiness, and morale as a state translated from the Greek as “well-being”. Aristotle’s definition incorporated both emotions and activity,

much like the modern definition of quality of life which links it to both emotional and functional components. Aristotle acknowledged that what we call quality of life differs for each person and that quality of life can change as personal circumstances change. (Fayers & Machen, 2000)

The expression “quality of life” appeared in public discourse in the early 1900’s and this implies a common public understanding. (Fayers & Machen, 2000) In 1948 the World Health Organization linked health and quality when it expanded its definition of health “to be a state of complete physical, mental, and social well-being, not merely the absence of disease”.

Quality of Life as an Outcome Measure for Medicine. Quality of life as an outcome measure represents a new paradigm for evaluating health, disease, and treatment success or failure. (Congressional Federal Register, 2008) Evaluation of patient quality of life allows us to understand the total effects of treatment and disease from the perspective of patient experience. A common dichotomy reflected in the literature differentiates disease and illness. The literature describes disease as physical and illness is as the patient’s experience of physical disease. Patients experience illness as the combination of disease and treatment, while physicians concentrate on the pathophysiology of physical disease.

Williams (1989) discusses factors in modern medicine that are driving the current focus on quality of life issues:

- Chronic illness and disability are emerging in the United States as our greatest health challenges as deaths from infectious disease declines with better treatment options.

- There is a change in demographics in more modernized nations toward the elderly as individuals tend to live longer and as birth rates decrease.
- There is a growing awareness that using only morbidity and mortality data poorly represents the health status of a population.
- There is a shift in illness patterns from acute to chronic that results in a transition from cure to care.
- There is an increasing need for defensible criteria for resource allocation of health dollars.
- Policymakers are placing greater emphasis on evaluation of patient satisfaction as an outcome.

Presently there is a move away from traditional outcome measures in clinical practice to the measuring the consequences of disease. Quality of life for the patient is based on his or her personal values, subjective experiences and individual perceptions of life compared with personal expectations. (Burkhardt and Anderson, 2003)

Dialysis as a treatment for renal failure and patient quality of life intersect. For the chronically ill patient, attending only to the disease process may not be effective when the disease symptoms are amplified by the patient's psychological response. (Schipper, Clinch, Powell, 1900, p. 12) Dialysis is a treatment for renal failure whose design and purpose is to preserve life. Yet values and not just science alone inform patient and decision-making regarding dialysis.

Treatment Futility. Any decision to withhold or withdraw treatment for renal disease is complex. Weighing the prognosis and the co-morbidities, the patient, the physician, or both may conclude that dialysis represents futile treatment for end stage

renal disease. The construction of the concept of medical futility is often split clinically into physiologic and evaluative futility. Physiologic futility is basically “Will it work?” Does the treatment promise cure or acceptable control of symptoms? Evaluative futility can best be understood as “Is it worth it?” How do the burdens and risks of treatment balance out against real or possible benefits? The traditional assignment of decision making roles has reflected a socially constructed split of expertise. The physician has typically held decision-making authority over physiologic futility. Patients and families traditionally assume decision-making authority in matters of evaluative futility. In cases of conflict, the physician and medical science have been typically privileged over patient values. Placing medical science over patient perception allows patient quality of life to become an outcome secondary to medically determined treatment goals. (Back, et al, 2005; Back & Arnold, 2006; Cantor, et al, 2003; Goold, Williams, and Arnold, 2000; McKee, Weinacker, and Raffin, 2000; Rubin, 1998; Zucker, 1997).

Economic, geographic, and cultural factors impact the social construction of futility. For example, in the United States the legally defined “reasonable man” standard of judging situations when used to determine universal futility differs if applied to a cultural understanding of disease. Restoring harmony may be seen by a “reasonable scientist” as futile treatment for a neurological condition but be seen as very relevant to a Navajo elder. Conceptions of autonomy and individuality are bounded by culture, whether familial or societal. Outcomes are also bounded by time and space. As medical technology advances, diseases may be physiologically futile today may be cured tomorrow. Geographically, a treatment like dialysis might be commonly available and supported with public resources in the United States but be scarce or nonexistent in

Africa, Asia, or South America. Since the focus of this project is dialysis-related quality of life for patients in the United States, an understanding of how a patient perceives the utility of treatment is necessary to inform policy and program decisions regarding allocation of health care resources. (Epstein, 1999; Fine & Mayo, 2003; Hallenbeck, 1999)

Ethics of Medical Futility. Acknowledgment that decision-making in medicine is complex and ambiguous leads into a discussion of medical ethics. Both patients and physicians often make the assumption that physician expertise can generalize from the physiologic criteria for futility to the evaluative criteria for futility. However, the decision as to how much ambiguity is tolerable is a medical choice which, under the ethical principle requiring each patient be fully informed, should be made by the patient. The reality is that often patients are only offered choices of treatment options that physicians have already decided hold a medical utility rather than being offered a full range of options. (Levinsky, 2001; Montgomery, 2006)

Any assumption that patient values and goals align with those of the physician is problematic. Bioethics has taken a clear stance of respect for autonomous decision-making when negative rights are invoked to withhold or withdraw treatment. (Helft, Siegler, and Lantos, 2000) Positive rights to treatments the physician has decided are futile are less well championed as a patient's legal or ethical right, even though autonomy is still the guiding principle. Patient perception of the value or quality of life may more closely match a patient's autonomous goals than outcomes measured in terms of functionality or cure alone. (Helft, Siegler, Lantos, 2000; Council on Ethical and Judicial Affairs, 1999)

Physicians are required by medical ethics to only decide that a certain treatment is futile when it does not help to attain the *patient's* goals for treatment. Importantly, patients do not always judge the efficacy of treatment by physiological outcomes measured separately from quality of life outcomes. When a physician makes decisions regarding whether or not a given treatment would be futile based on his own values is hard paternalism. When a physician makes the decision that a treatment is futile based on the physician's beliefs about the patient's values exemplifies soft paternalism. Such decisions without discussing treatment options with patients can violate the physician's ethical, moral, and legal responsibilities to patient autonomy. (Goold, Williams, Arnold, 2000; Council of Ethical and Judicial Affairs, 1999)

The physician may ethically determine whether a patient's goal is physiologically realistic. Ultimately however, the goals of treatment depend on the values and perceptions of the patient. The physician's decision should include what value the treatment holds for the patient and how it contributes to blocking or attaining the patient's goals and not just the traditional goals of medicine preventing or curing disease. A patient's goals may change from pursuing cure to symptom control, maintenance of autonomy, or preserving meaningful social connectedness. (Loewy & Loewy, 2000; Goold, Williams, Arnold, 2000)

Shared perspectives, values, and decisions about treatment options come from an open physician-patient dialogue about patient goals. The physician can use this conversation as an opportunity to discuss candidly treatment options and his recommendations and reasoning. But conflict over decision making can arise from family dynamics, financial concerns, ambiguity or disagreement over prognosis, and

physician, family, or patient psychological defense reactions. In its extreme, this conflict can result in family members or providers either emotionally withdrawing or insisting on aggressive treatment beyond any utility to the patient. But the utility of any treatment is best determined by how the patient assesses his quality of life—a life he alone experiences.

Obligation to Assess the Quality of Life in Health Care. Based on the ethical principle of beneficence, acting for the good of others, the central purpose of therapeutic innovation is to develop therapies that will accomplish the goals of curing or preventing diseases or of ameliorating their manifestations”. (Levine in Spilker, 1990, 153)

Privileging patient goals leads practitioners directly to the ethical standard of doing no harm and its correlate of maximizing benefits and minimizing harm to the patient. The ethical principle of respect for persons also guides medicine’s responsibilities to patients. Respect for persons as an ethical principle includes the concept of personal autonomy. To respect personal autonomy is accomplished by honoring the each person’s opinions and choices, unless, of course, those choices harm others. “Autonomous persons live according to life plans which reflect their conceptions of what it means to live a good life.” (Levine, 1990, 157; (Loewy & Loewy, 2000; Fulford, Dickenson, Murray, 2002)

The Practical Utility of Information. Medical ethics require physicians to provide patients with any information which could be used to understand a treatment’s impact on patient quality of life. The ethical idea of practical utility is closely linked to the legal concept of materiality. Material information due the patient would be any information to which a reasonable person might attach significance. Thus, information is material, or has a practical utility, if it might affect the patient’s decision to accept to

reject a particular therapy. Information might hold practical utility for patients if a given therapy would have one or more negative impacts on patient quality of life. The degree of impact on quality of life of inherently different therapies can be compelling to the patient, especially when the duration of impact is considered. In chronic disease, the length of negative impact on patient quality of life often becomes material information in a patient's decision to accept or decline treatment. (Levine, 1990)

If a therapy for an illness is life-saving and likely to restore the patient to a pre-morbid health state in a reasonably short period of time, then the patient's quality of life becomes less of a concern in treatment planning. The thought is that if a reasonable person would choose the therapy's advantage, even with transient side effects, then assessment of the therapy would not require the inclusion of a quality of life assessment. Ultimately though, the fact that a therapy can claim to be life-saving is not in itself justification for failing to evaluate the patient's quality of life since the reasonable man standard could allow for a patient to refuse the therapy, i.e. long-term ventilator therapy or full code resuscitation response when recovery sufficient for the patient to leave the hospital is unlikely. (Levine, 1990)

The ethical criterion of justice can be applied to a decision for the physician to include patient quality of life as an integral part of his or her planning and treatment goal setting without consideration of patient age, gender, ethnicity, etc. The justice criterion requires that the burdens and benefits of acts be distributed fairly and equitably to each patient. In 1983 the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concluded that each person has an

ethical right to equal access to appropriate health care. The President's Commission determined that just health care access:

...will take into account the value of various types of health care in relation to each other as well as the value of health care in relation to other important goods for which societal resources are needed. Consequently, changes in the availability of resources, in the effectiveness of different forms of health care, or in society's priorities may result in a revision of what is considered as adequate [health care].

As health care costs command a greater percentage of national, and by extension global expenditures, they may require an ongoing determination of health as a value in relation to other valued societal goods. As values shift societal priorities, public policy can be expected to follow. In choosing, for example, how or if to fund research into alternative therapies or to determine access to existing therapies, it becomes critical for decision-makers to have all the relevant information on morbidity, mortality, and patient quality of life in order to make a true cost-utility analysis. A quality of life assessment in addition to mortality and morbidity statistics is needed in order to be of ethical use to public policymakers. (Levine, 1990)

As a treatment for renal failure, hemodialysis is expensive, in a time of increasing concerns about health costs, and, as well, extremely rigorous and invasive treatment for patients to endure. The combination of public and personal costs mandates the inclusion of quality of life assessment.

A Self-Determined Quality of Life Assessment. The seminal literature on quality of life reflecting the subjective values of participants for my study is Hadley Cantril's *Patterns of Human Concerns*. His 1965 study was large in scope with over 2,000 participants conducted in multiple countries. Cantril developed and used the Self Anchoring Striving Scale in that study to describe and understand individual fears and

aspirations free from preset researcher criteria. Cantril introduced his findings, “It is because of man’s desire to enrich the value of satisfactions of his life that human motives have the great variety, subtlety, depth, and complexity they do.” (1965, p. 10).

The Cantril Self Anchoring Scale allows participants to determine where they place themselves on an Osgood’s differential scale with two anchoring extremes—the best and the worst situation possible. Cantril argued that how participants rank themselves reflects personal values and the perceived likelihood of satisfying those values. Both values and how possible it seems to satisfy them come from culture, life history, intrapersonal characteristics, and social characteristics.

Cantril sees these personal standards as impacting individual decisions. “More reliable predictions of what people want or do not want, believe or do not believe, will accept or will not accept, should aid [treatment decision making]”. (Cantril, 1965, 3) The ability of Cantril’s Self Anchoring Scale to describe patients’ quality of life lends the instrument great power to understand patient assessment of what makes a quality life. (Cantril, 1965)

Cantril discussed what he termed individual, subjective “reality worlds” as a “matrix” of human concerns and aspirations which guide behaviors and determine value satisfactions. Reality worlds can change radically within an individual’s lifetime with evolving circumstances. The evaluative difficulty is to apply individual quality of life standards of the individual being evaluated rather than evaluating them by the researcher’s own criteria which may be biased by experience of the researcher. Clearly then, an accurate assessment of this individual reality world is blocked by use of an

instrument which asks the participant to make choices or selections between categories, alternatives, or situations predetermined and selected by the researcher.

A self-anchoring scale provides a simple, adaptable technique for eliciting the unique reality world of an individual. In its purest form, a participant is asked to define, based on his or her own assumptions, perceptions, goals, and values, the two extremes or anchoring points on the scale. This participant-defined continuum would then be used as a measurable scale. Cantril described as the top anchoring point the best possible life. At the other extreme, he placed the worst possible life the participant could imagine. The participant then placed him or herself on a rung in the ladder schematic between the two extremes. Cantril believed that this self-placement would best represent the hopes, fears, values and beliefs that constituted the participant's subjective world.

Cantril's research describes basic commonalities among diverse peoples: the satisfaction of survival needs, living a life that constitutes well-being, physical and psychological security, order and certainty sufficient to be predictive of the consequences of actions, and a sense of internal stability provided by habitual behaviors. (Cantril, 1965) Cantril's research also found common to diverse respondents a desire for a sense of accomplishment and the satisfaction of successfully handling new challenges. Individuals can achieve this sense of accomplishment two ways. The first is through "value satisfactions that are essentially new, different, more efficient, more reliable, more pleasurable, or more status producing results of activity along familiar and tried dimensions." (Cantril, 1965, p. 317) The second way to achieve a sense of accomplishment and value satisfaction is through activity that is "new in the sense of

being emergent, new qualities people discover or create themselves for the first time” often in response to new challenges. (Cantril, 1965, 317)

Cantril describes the human capacity to make choices and the autonomous will to exercise this capacity to choose according to their hopes and fears, their subjective worlds. A common human need is the freedom to make the choices and decisions within their perceived locus of control. “Psychologically freedom refers to the freedom to experience what is potentially available...to be and to become” within those potentialities. (Cantril, 1965, 317)

The Cantril Self Anchoring Striving Scale known as the Cantril Scale or the Ladder Scale is a simple, widely applicable assessment method for researchers or medical care providers to capture the unique reality of each research participant or medical patient. The Cantril Scale can be used to assess individual perceptions of global quality of life as well as to assess perceptions of specific aspects of quality of life. The Cantril Scale presents a ladder scale model with typically ten rungs. The top rung of the ladder represents “the best possible...” and the bottom rung of the ladder represents “the worst possible...” The two end points are not defined by the researcher and definition is left to the participant. For global quality of life questions, the top and bottom researcher statements should be general, i.e. “Where would you place your quality of life in general?” More specific quality of life questions would use questions more specific to the research questions. “Where would you place your quality of life on dialysis?” for example. The Cantril Scale can be present, future or retrospective depending on the initial question or instruction. “Where would you place yourself in [a year, five years, etc]?” A retrospective question would ask the participant to place himself on the scale at

some time in the past. “Where would you place yourself before your diagnosis [or before you began treatment, etc.]” A self -defined scale could be used as a pre-post, retrospective, or future oriented assessment for individuals, families, or communities. (Cantril, 1965; Campos & Johnson, 1990)

It is important that a self-anchoring scale allows the participant to define his quality of life based on his subjectively held assumptions, aspirations, goals, and values relative to his own anchoring points. Using a participant-anchored scale, quantitative scores reflecting the participant’s chosen ladder rung in the Cantril Scale can assess participant responses or changes to evaluate interventions. This may be more valid than assessing participant responses to a set of criteria chosen by the researcher. Rich data can result from a qualitative analysis of participants’ responses to research questions. Open-ended questions can elicit participants’ lived experience. Further, semi-structured questioning into why participants place themselves on a particular rung of the ladder can explore in depth the subjective material. Quality of life measures that rely solely on clinical judgment for a priori content may fail to determine quality of life as patients experience it. (Compos and Johnson, 1990)

Human Needs: Human beings need to experience a sense of their own worth and to know they are valued by others, that their actions make some sort of difference in ways that produce a sense of personal satisfaction. Personal identity derives from family, friends, and social relationships, which make it possible for individuals to situate themselves in both past and future contexts. This process of contextualizing the self in time allows individuals to project themselves into larger dimensions beyond this life’s existence or experience. People seek some value or belief system to which they can

commit themselves. (Martz & Livneh, 2007) As they face the uncertainties of life, it is part of the human condition to desire some anchoring points. Those internal, subjective anchoring points can be captured by research use of the Cantril Self Anchoring Striving Scale. This understanding of quality of life as it is subjectively defined by chronic disease patients provides a critically important dimension to those traditionally understood as dimensions of health care outcomes.

Ways of Understanding: The Dimensions of Health Outcomes. There has been a shift in patient health outcome assessment from a reliance on measures of medical process toward measures patient quality of life assessment since Medicare included in their Conditions of Coverage in 2008. These patient-centered assessment measures align with generally accepted patient goals: life; the ability to function normally; freedom from physical and psychological, or social symptoms; and financial stability. (Schipper, Clinch, and Powell, 1990) These patient goals translate into five measurable dimensions: death, disability, discomfort, treatment side effects, and economic costs. In order to devise a hierarchy in which the health outcome dimensions can be viewed as both exhaustive and exclusive, the definitions must be broad enough that any specific health-related aspect can be placed in one of the five dimensions. (Schipper, Clinch, and Powell; 1990)

These five dimensions of health outcomes can be broken down even further into sub-dimensions. Death, for example, can be related to cause and can also reflect an average length of survival from a particular disease process as well as age-related life expectancy. Average life expectancy varies with gender, socio-economic status, and area of residence. Disability can be quantified in terms of percentage of functional loss. And

side effects of treatment for disease can be attributed to varied causes. Side effects can be from pharmaceutical effects, surgery, emotional responses, or nonsurgical treatments, for example, radiation therapy or dialysis as a renal replacement therapy. The economic dimension of health outcomes can include direct costs of treatment or indirect costs such as loss of income. The sub-dimensions of health outcomes can then be examined as component parts or as variables of interest to quality of life researchers. (Schipper, Clinch, and Powell, 1990)

Productivity Outcomes. Economic theory has been used to measure human productivity and in terms of human capital assessments to evaluate both patient health outcomes and to compare treatments. Cost effectiveness analysis can be used to compare broadly or narrowly-defined units of health outcomes, i.e. adjusted life years or urea reduction rates and the dollar outlays necessary to achieve them. Economists also can approach the issue of health care outcomes from a mortality perspective—how many lives are lost to a specific disease, for example. (Kaplan & Bush; 1982)

How to economically quantify the outcomes for patients with a shortened life expectancy or outcomes when quality of life is diminished presents a different problem. One answer is predicting adjusted life years or well years. Kaplan and Bush define a well year as “the equivalent of a completely well life, or a year of life free of dysfunction, symptoms, and health related problems.” (1982, 65) The effectiveness of therapies and programs can be compared quantitatively by comparing results in well years.

Although the concept of well years can seem egalitarian, with a well year holding the same social value regardless of economic or social attributes, the intrusion of researcher values into any definition of a “completely well life” is inescapable. The idea

of equivalent well years as value neutral ignores inherent health differences and behaviors in different social and economic groups. Low income people may have poor nutrition and scarce health resources which impact well years available to the individual member. (Schipper, Clinch, and Powell, 1990)

This cost effectiveness model of treatment evaluation lacks recognition that disease states do not necessarily provide a direct influence on subjective patient perceptions of the satisfaction, desirability, or utility of life. The physician's privileging of the pathophysiology of disease can lead to neglect of the patient's lived experience and a differing valuing of illness. Physiologic and psychological dimensions do not act independently. One can and often does influence the other. Many variables come into play in the experience of illness. How the patient perceives disease symptoms and adverse reactions to treatment and how the patient constructs symptoms, treatment reactions, and the disease itself impact his or her experience of illness. Also important to the experience of illness are the fit between the patient's ability to cope with chronic disease and its demands. A good fit can lead to a sense of control and a poor fit can amplify both the physical and psychological impacts of disease. (Schipper, Clinch, and Powell, 1990)

Combining utility measures in a quality of life analysis with cost-effectiveness analysis can produce a hybrid cost-utility analysis model. The outcome is a comparison of treatment costs to a gain or loss in quality of life measured as physical, social, economic, emotional, or ethical impacts. Cost-utility analysis can include mortality, morbidity, and quality of life effect. (Feeney, et al. 1990) Cost-utility analysis can inform

patients and providers in a micro sense as to one element of health care decisions.

Policymakers and health care funding sources can use the analysis in decision-making.

Well-being can be an alternate way of evaluating a health care decision.

Shumaker et al. (1990) use a general sense of well-being and satisfaction with life as a definition of quality of life. The dimensions that these authors use to determine quality of life are cognitive, social function, physical function, emotional-psychological status, personal productivity, and intimacy. Personal productivity includes both paid and unpaid functions, and role/ social relationship contributions. The intimacy dimension intertwines with the emotional/psychological dimension in relationships defined as close by the individual. Each dimension can be examined from a subjective and/or an objective/external orientation.

Multiple factors influence Schumaker's quality of life dimensions. They can be divided in three broad categories. For example, contextual factors include geographical setting, socio-economic factors, and cultural factors. Interpersonal factors include social support, relationships, and stressors such as employment and finances. The intrapersonal factor category includes many classic psychological factors such as coping skills, personality variables, personal values, and experience of symptoms. Each factor can be represent patient goals, and this makes them measurable severally (disease specific batteries) and jointly (general batteries) and in representative populations or individuals. (1990)

One method of conceptualizing quality of life situates a person on a continuum of function describing impairment, disability, or handicap. The growing prevalence of chronic disease in the United States sharpens interest in living well with a chronic disease

when cure is not a viable goal. The assessment of physical and mental functioning has increasingly become a part of medical evaluations. Clinicians and researchers work to develop scales that measure functioning using standardized criteria. (Schumaker et al., 1990) The World Health Organization (WHO) has offered a classification system that researchers can apply in order to standardize the approach to health care questions that regard human functioning. They define impairments as any physical or mental abnormality. The WHO classifies any restriction in performing activities in a manner or range considered normal as a disability. Disability in common usage is divided into two domains—inability to conduct work activities and impairment of activities of daily living or function. Handicaps result when impairment or disability prevents normal role fulfillment. The WHO classification attempts a definition which can be applied in a culturally neutral manner. (Spector, 1990) This study applies a much broader range of criteria which relies on patient subjective conceptualization of impairment within their cultural context.

Cultural Relativism. Given the globalization of modern life, a culturally sensitive measurement method for quality of life has never been more important. Even though the social sciences use culture as a defining concept, no one accepted definition exists. According to Campos and Johnson (1990), culture includes shared conception of reality, shared perception of reality, learned and shared interpretation of the world, concepts of value and desirability, prescribed roles, ideals, and expectations. Societies are complex and diverse. A society which seems on the surface to represent a single culture may actually represent many distinct cultures defined by race, age, gender, socio-economic status, ethnic origins, etc.

Research conducted within a framework of cultural relativism can acknowledge and correct for researcher beliefs originating in an ethnocentric value system. Cultural relativism accepts that some values can be considered universal, for example, food, shelter, or safety. No absolute standards are in place, however, to judge quality of life across cultures. Without an understanding of the subjective aspects of quality of life, research based on objective measures alone can fall short of understanding how culture contributes to an individual experienced quality of life. Objective measures such as housing, income, education, religious freedoms, or political systems vary tremendously between and among cultures. Subjective research approaches avoid linking quality of life to absolute variables and to instead assess qualitative quality of life perceptions. (Campos and Johnson in Spilker, 1990; Cantril, 1965)

Summary: As health care faces the challenge of treating chronic disease rather than treating acute disease, medical therapies are increasingly being evaluated for their response to the needs of chronically ill patients of all cultures. Quality of life is becoming as important an endpoint for treatment as cure. The distinction between disease as a measurable bio-physiological abnormality and illness as the subjective experience of disease can be of great utility for quality of life researchers. Subjective measures intended to measure quality of life can include intra-personal, social and cultural factors. Subjective assessment of quality of life reflects the complex interplay of all three. (Campos and Johnson in Spilker 1990) Using a patient's quality of life to assess therapies can assist health care providers to contextualize treatments based on the values and goals of each patient. (Pearlman and Jonsen, 1985)

Data regarding physical, psychological, somatic, or combined responses is necessary to evaluate or compare therapy options. Health care and medical research requires a method which can compare data from diverse areas of medical inquiry if it is to measure therapeutic response. If objective measures are not reliably valid cross-culturally or between social groups as Campos and Johnson suggest, then it is important to identify a subjective quality of life measure. The Cantril Self Anchoring Striving Scale is a measure which can be used in either research or clinical practice to investigate how patients perceive their quality of life without imposing cultural standards or practitioner/researcher bias. (Campos and Johnson, 1990)

As medical advances in highly developed countries like the United States extend life beyond the wildest dreams of past centuries, quality of life becomes the greatest challenge of this one. This project is an ethnographic qualitative research investigation of how patients' perceive their quality of life on hemodialysis as treatment for end stage renal disease.

Chapter Two

Introduction

Some qualitative social science researchers express concerns that a review of the literature might impose existing theories and interpretations on the data. Strauss and Corbin (1990) acknowledge that researchers bring to any study both life experience and a background knowledge of professional literature. Conducting a literature review before conduction of a qualitative study serves only to orient the researcher within a broad research problem. The researcher then organizes broad literature categories which could inform aspects of the research problem. This literature review reflects those research areas which initially informed aspects of the research question. I extended the literature review during the constant comparison process as theory began to emerge. The emerging theory further compared to existing literature to increase understanding

Coping and Social Support. Research on coping has traditionally focused on intra-psycho defense or trait based assessment of patient functioning within a context of psychological pathology. More recent research focuses on coping as occurring in the aftermath of crises and traumatic events. Coping efforts reflect a search for meaning, a way to make sense of losses, positive reappraisal of quality of life, and finding personal or societal benefit. (Livneh and Martz, 2007) The study of coping has evolved to include a more interactive and process-oriented assessment. This more dynamic model of coping research includes individual perceptions, cognitive abilities, availability and quality of social support, and environmental factors. An integrative conceptual model for coping with chronic illness and disability includes an environmental system, a personal system, crisis or trauma specific factors, and health-related outcomes. (Moos and Holahan, 2007) The social context of coping allows researchers to examine coping as an interdependent effort. People and, more broadly, society are seen as offering not only support for individual coping efforts, but also in collaborative coping efforts. (Kosciulek, 2007)

Social coping efforts for persons with chronic illness include maintaining or regaining a sense of normalcy; adjusting to altered relationships; accommodating necessary role changes; addressing possible social stigma; and maintaining a sense of agency. Normalization might require the patient to reframe a chronic disease as merely a life circumstance whose signs and symptoms are manageable. Normalization is fostered when a patient's social network validates his or her continuing capacity to maintain usual functions, relationships, and abilities. Human relationships may be altered when time, physical, or mental demands of chronic illness constrict patient participation in social events or usual social roles. Role changes for persons with chronic illness can result in

role losses or illness-related replacement roles. Patients might need to develop new roles outside of medically dictated ones to replace previously occupied social roles.

(Kosciulek, 2007)

To understand coping in the face of chronic illness, it is helpful to look at coping strategies in terms of patient goals. Patient goals for coping are several. First is to acquire accurate information about both social and physical demands of the illness. The second goal is to acquire or maintain the psychological resources needed to process information on the illness and treatment options. Resources must also be sufficient to initiate action based on information ensuring agency. A further goal is to meet the demands of the illness and to reduce threat to self or others. How the illness is perceived by the patient is crucial to his ability to develop coping strategies aimed toward mastery necessary for the patient to return to pre-illness psychological and social states. (Livneh and Martz, 2007; Baumeister, Leary, 1995)

For researchers attempting to better understand chronic illness, the study of social support is important as a factor in understanding the patient's well-being and function—his quality of life. (Sherbourne and Stewart, 1991; Cohen & Wills, 1985) Thoits (1986) links coping and social support and urges a view of social support as coping assistance. Thoits points to common functions of social support and functions of coping. Instrumental functions include aid in finding tangible resources. Emotional functions include resources necessary to resolve emotional problems. Perceived support includes coping support that can alter the patient's perceptions of important aspects of the crisis. These altered perceptions can include cognitive reappraisal of the health crisis. He further hypothesized that strategies to further coping used by individuals are the same

strategies that they will use to offer assistance to others completing the linkage of efforts. (Livneh and Martz, 2007) This cyclical coping assistance was described by hemodialysis patients in the current study. Patients both offered and received support from other patients helping them to anticipate and cope with the challenges of chronic illness.

Hobfall's Conservation of Resources Theory suggests that resources are those things people value or that preserve what they value. The main goal of resource conservation is to maximize gains and minimize losses. Social systems offset resource losses by constructing other resources necessary to develop a strong coping strategy. The socially constructed coping resources facilitate both individuals and groups in creating coping strategies. Berg, Meehan, and DeViney describe a coping model in which individuals and social groups use shared influences for reciprocal problem solving. They suggest that coping is embedded in a social context that provides both appraisal and collaborative efforts to cope with normal stressors and specific stressors such as chronic disease. (Livneh and Martz, 2007)

Folkman places coping within a contextual model where coping can be assessed in relational terms specific to the stressor. The main underlying assumption made by the contextual model is that actions and thoughts seen as coping strategies are determined by the relationship between the person and environment created by the stressor. This person-in-environment focus for coping begins with appraisal of the person-environment relationship, including the significance of the stressor (primary appraisal) and possible response options (secondary appraisal). These ongoing appraisals result in changing strategies for coping. Strategies may address changing the stressor, changing attributed meaning of the stressor, or changing patient cognitions about the stressor.

Contextualizing coping presents challenges to researchers in determining which aspects of coping are to be measured in order to understand their relationships with outcomes.

(Folkman, 1991)

Cohen and Lazarus identified five adaptive patient coping tasks specific to illness. Patients should reduce personal harm and enhance recovery prospects. Patients adapt to and learn to tolerate negative realities. Patients acquire and maintain a positive self-image. Patients maintain personal emotional stability. And patients maintain positive and available relationships with others. At a conceptual level, normative coping tasks can be identified for varied stressors. Coping responses, however, will vary with individual values, beliefs, and goals.

The interpersonal context of coping with illness can be operationalized as social support. Social support can influence how an individual patient adapts to illness, and some research shows social support as influencing the outcomes of illness. Rowland organizes assessment of social support: type of support, source of support, availability of support, quality of support, and how the patient perceives the need for support.

(Goodheart and Lansing, 1997) The typical social work assessment of patient social support done in dialysis incorporates Rowland's organization. Missing is the patient's own assessment of the status of support.

One study on end stage renal disease patients new to dialysis parameters found that the capacity to provide relationship support decreased mortality during the first year. This study found that the perception of being able to offer support remained what the authors felt was a significant variable for studying mortality. (McClellan, Stanwyck, and Anson, 1992) Although the study looked at a population, first year dialysis patients,

excluded from the study parameters of this project, its findings are important to a review of support literature.

Tangible support, such as financial support or transportation and educational support, is among the types of social support patients find important. Social support provided by others perceived as significant by the patient can help through anticipating problems and determining the probable effectiveness of solutions. They can also aid in reinterpretation of the disease and in minimizing the patient's negative emotions. The most valued types of support fit into the emotional-affective category. Affiliational support can help patients achieve mastery of their disease. A sense of belonging comes from positive affiliational support and can prevent patient identification with the illness role. Most often the source of emotional-affective support comes from family but can originate within other groups. The needed quantity and quality of support received should be assessed from both the perceptions of the patient and, equally important, from the perspective of the support provider identified by the patient. (Goodheart and Lansing, 1997; Sarason & Duck, 2001; Metz & Livneh, 2007)

Chronic illness presents changing, expanding, and long-term demands which can challenge the resources of the family. Most research has evaluated the effects of group counseling. Peer counseling helps members adjust to the challenges and losses brought about by chronic illness. The "power and potential" of groups lies in bringing patients together to meet a mutual set of needs. Patients who participate in disease support groups are able to develop a peer system that can potentially aid in developing coping strategies. (Power and Dell Orto, 2004) "Instead of specific people, whole groups might function as

sources of perceived support...A sense that one belongs and matters to others may depend on the homogeneity or cohesiveness of such groups.” (Thoits, 1995, p. 67)

The idea of group support systems can add an element of reciprocity to the study of social support and chronic illness. Traditional roles of spouse, parent, sibling, worker, etc. may be stressed by the demands of chronic illness and expectations regarding those roles may be impossible to meet. The illness role of patient may be defined as part of society’s understanding of medicine and the physician-patient relationship. Mutual help groups often serve as an interpersonal attempt to satisfy basic needs of autonomy, relatedness, and competence. Providing social support to others helps mediate each of these needs and can increase individual perception of well-being. (Weinstein and Ryan, 2010)

Any situation which is perceived as negative and holding possible harm, such as illness, can increase the need to connect with others. A threat to social connections such as those which can occur with chronic illness has been proven to cause anxiety and depression. Patient anxiety about death can threaten feelings of social belonging. Groups are effective in providing a new avenue to social connectedness for chronic disease patients and fill a substitution function for relationships lost through chronic illness. (Baumeister and Leary, 1995)

Offering support to others is perceived as having a positive impact on inter-relatedness. Social relatedness, in turn, can promote intimacy between support givers and recipients. When mutually rewarding interactions occur, all parties can have the subjective experience of mattering to the others. The support giver may gain recognition and the perception of importance and being relied upon by both the support recipient and

expectations for the support giver. Cultural expectations of fulfilling a role which do not include accepting help can act as a barrier. Cultural expectations can differ for families as well as societies. The support interactions may be cyclical, with support providers, in turn, receiving help in meeting their needs in dealing with the illness from those to whom they give support. (Weinstein and Ryan, 2010; Sarason and Duck, 2001)

Giving Support. Research offers a mixed picture of the costs and benefits of providing support to others. Positive effects are found for support providers when the interactions are positive in nature, i.e. companionship. However, research on support provision to patients who evidence signs of depression, anger or anxiety show strong evidence of increased anxiety and depressive symptoms in the support provider. (Brown, et al, 2009; Strazdins & Broom, 2007) In addition, research that addressed the amount of support provided to patients and found increased feelings of burden and frustration in support providers, even when societal role expectations for support provision are high, i.e. with spouses and parents of patients. (Thomas, 2009)

Giving support to others can also be understood by examining autonomous helping. The support giver is not responding to societal norm expectations, but is rather satisfying internal needs. Autonomous pro-social acts can contribute to a congruent sense of self and positive self-esteem. Self-endorsed support giving enhances feelings of efficacy and competence and can facilitate positive interactions and connectedness. (Weinstein and Ryan, 2010) Autonomously offering social support to others can help individuals meet the adaptive tasks of chronic illness. Self-initiated helping can aid the patient in tolerating negative realities, maintain positive self-image, stabilize

emotional/affective states, and create or maintain satisfying relationships. (Folkman, 1991; Gaskins & Brown, 1997)

Social Construction of Support. Taking a socially constructed perspective on why we help others allows an examination of individual social support efforts as embedded in a rich social context. We widen the perspective of coping and social support research to a self-in-society or person-in-environment focus. Patient goals and values are contextualized within family goals and values. Social support is seen as complex, reciprocal, and affecting the individual, dyadic, group, and network levels. Whether or not support is perceived as appropriate is a joint production of personal characteristics and the social environment. (Sarason & Duck, 2001; Weinstein and Ryan, 2010; Thoits, 1995)

Social Constructionism as a Research Paradigm. Social constructionism is one of several interpretive paradigms concerned with how people internally construct their worlds and their place in them. Constructionist researchers study the constructions or meanings individuals give to phenomena. All knowledge comes from individual or societal perspectives. There are two broad research approaches to use when examining construction of reality. The first approach focuses on personal constructions—individually experienced meanings. The second approach, social constructivism, focuses on shared social constructions of meaning and reality co-constructed by individuals and society. The philosophy underlying social constructionism is that human beings have the ability to interpret and construct their own reality. (Williamson, 2006)

One criticism of constructivism is that its internally constructed reality leaves no room for inclusion of concrete biological and physical realities. In less strictly

understood social constructivism, external realities are accepted as real but seen as contextually constructed rather than absolute. As a research paradigm, social constructivism expresses an ontological relativity. In other words, individual experience of reality is relative to many contextual factors. Experienced reality depends on individual history, gender, race, status, society, or culture. Constructivism holds that no two people exist in the same empirical world. Each person's reality is mutable and constantly changing rather than objective and statically known. (Williamson, 2006; Krause, 2005)

The core of social construction is a belief that human reality differs from the physical world and needs to be studied in a different manner. Human perceptions of reality may not meet positivist objective research criteria, but they are valid constructed and experienced reality. Socially constructed views of health, medicine, and the body are produced through human interaction and interpretation. They may change or be reinterpreted over time or as health circumstances vary. What is known scientifically about the physical body is inseparable from how the body and medicine are socially constructed. Illness is a subjective construction by individual in a society rather than an objective definition of pathology. Constructionist research studies interpreted human realities and the implications of individual health constructs on social actions and interactions. For a quality of life researcher, social constructionism offers a lens into not just disease but also a lens into the patient's perception of illness. (Williamson, 2006)

Incorporating constructionist research principles into health care research broadens the scope of treatment considerations and outcome measures, or at least the understanding of patient's experiences. It can provide the means for individually

experienced reality, the lived reality, to influence treatment decisions by the physician and patient. Social constructivism can answer policy interests in health care evaluation by including the patient's quality of life in that evaluation. Constructionist researchers now offer an alternative definition for health and illness that incorporates more than mortality and morbidity. A constructed reality of chronic disease might be very different when experienced by the physician and when experienced by the patient. The patient's family, other physicians, patient families, or even other patients with the same disease may experience the illness in radically different ways. Using multiple perspectives, we can envision multiple treatment goals and outcomes. At the very least, they can problematize the pursuit of a single treatment goal. In chronic illness, the constructed reality of the patient can balance goals for extending the quantity of life with goals for the quality of life. (Smith, 2003; Warren & Karner, 2010; Denzin, 1989; Nettleton, 2006; Williamson, 2006; Krauss, 2005)

Social constructivist researchers use discourse analysis to study the ways language shapes reality. This analysis of health discourse is especially relevant in understanding the social constructions around health, the body, and medicine. Language reflects the social constructs of physical disease and experienced illness. Constructionist researchers deconstruct texts to illuminate the interactive influence of language. Analysis of medical discourse in our culture to date tends to privilege the power of physicians to define body, health, disease, and medical knowledge. Discourse analysis explores the production and application of medical knowledge and can as well reveal the roles of power, politics, and professions in response to disease and also to juxtapose such views

with perspectives of patients and caregivers. (Smith, 2003; Warren & Karner, 2010; Denzin, 1989; Nettleton, 2006; Williamson, 2006; Krauss, 2005)

From a social constructionist perspective, bias can enter research through the relationship of the investigator and what is investigated. Health-related quality of life for chronic disease patients is arguably subjective and so not bias free. Social constructionist research attempts to understand the different patient constructions of disease, illness, prognosis, and treatment options. Unlike more radical interpretivist research paradigms which question that there is a valid account of the physical world, social constructivism does not ignore the physical process of disease or negate the value of medical progress toward an objective knowledge of disease. The primary methods of social constructionist research, interviews and observations, can produce reliable results. Triangulation with documents can verify those results. (Smith, 2003; Creswell, 2003; Patton, 2002; Warren & Karner, 2010; Denzin, 1989; Nettleton, 2006; Gabe, Bury, & Elston, 2004; Williamson, 2006, Krauss, 2005)

Physician and Patient Relationship. A micro-context of end stage renal disease care is the relationship between the physician and the patient. The physician-patient relationship is embedded within cultural, social, political, legal, and financial constructs which provide contextualization for medical care. The role of the physician in diagnosing and treating illness is culturally defined. The cultural context of a physician-patient relationship reflects a power differential rooted in either actual or perceived knowledge of health and illness. Political, legal, and financial aspects of the relationship between physicians and patients are defined by a cultural system which dictates the ethics and principles of every medical practitioner-patient interaction.

Physician response to ethical dilemmas, treatment choices, and the very nature of the physician-patient dyad is shaped by physician participation in various systems. Physicians face cultural pressures from meso-level organizations such as the American Medical Association and physician supervisory boards. The macro level societal culture and the mixed meso/macro influences of Medicare and Medicaid also influence physicians. Micro pressures on the physician of more informal relationships with colleagues and mentors often impact the physician and patient relationship. Already complicated by multiple pressures, interpersonal conflict between physician and patient over medical goals and individual value systems can add further pressure on the functional capacities of the relationship. The patient relies on the physician-patient relationship for protection, good will, and medical information.

World Views. Patient world views can be conceptualized as a set of beliefs with a dual focus. World views help the individual to predict how the universe functions. Individuals also utilize their world views for self-orientation to chronic illness. Traumatic events such as chronic illness can challenge an individual's existing world views creating cognitive dilemmas as patients struggle to reconcile inner representations of selves as they experience chronic illness. These inner representations offer the patient both objective and subjective meanings to the trauma of life-threatening illness and treatment. Objective representations describe and explain how the universe functions. Subjective representations relate to the same function in how a patient perceives his or her own status and power. (Neimeyer, 2010; Van der Hart, Nijenhuis, & Steele, 2006)

Dialysis intensifies the cognitive dilemmas presented when patient world views are challenged by chronic illness, because it is an artificial way of living. Patients never

know when treatment will cease to be enough to keep them alive. Chronic illness often has a profound impact on the world views held by patients. Chronic illness typically shatters any fundamental patient assumptions about reality and self. For patients, end stage renal disease brings economic, social, and spiritual losses. It presents a concrete threat to their life and integrity. This threat can require the integration of profoundly negative experiential material into prior world view assumptions. Patients usually either assimilate these negative experiences into a pre-existing world view or restructure their world view in order to enable it to accommodate the traumatic experience. (Neimeyer, 2010; Van der Hart, Nijenhuis & Steele, 2006)

Conclusion: The literature provides insight on methods for better assessing and understanding many of the perceptive threads of a subjectively defined patient quality of life on dialysis. My study will ask dialysis patients to explain quality of life on dialysis as they live it.

Chapter Three

Research Methodology

Introduction

This is a study using ethnographic techniques within a constructionist paradigm to explore the self-perceived quality of life of dialysis-dependent end stage renal disease patients. Ethnography can elicit a rich picture of patient quality of life and can provide a way to get at in-depth patient perspectives. This chapter discusses the research process used to explore and better understand how dialysis patients evaluate their quality of life.

Definition of Terms

Quality of Life: An individually constructed satisfaction with life.

Patient: For the purpose of this study, a person at least 21 years of age with end stage renal disease on dialysis for over 18 months and not a renal transplant candidate.

Nephrology: Medical subspecialty concentrating on the kidney and its function.

Maintenance Hemodialysis: Renal replacement therapy accomplished through mechanical processing of blood to remove toxins and fluid.

End Stage Renal Disease: A terminal and final phase of kidney failure resulting from a variety of disease processes resulting in function dropping to below 15%.

Constructivism: One of several interpretivist paradigms concerned with the ways in which people construct their worlds including both individual constructions and social.

Delimitations

The participants in this study are adult hemodialysis-dependent end stage renal patients. The unit studied rarely treats pediatric renal failure patients. Participating patients at the time of research interviews had each been receiving renal replacement therapy for a minimum of eighteen months to include patients post adjustment to the chronicity of dialysis dependence. None of the participants were active transplant candidates and so expected that dialysis treatments would continue until their death.

Participants were limited to those receiving dialysis in one small hospital-owned dialysis unit located in the Northwest section of the United States due to time and financial constraints as well as providing improved researcher access to study participants.

Limitations

The results of this qualitative research study are not generalizable since exact replication of results would require replicable research parameters. The results, however, may be applicable to other renal disease patient populations. The results may also transfer to studies and interventions with like populations with chronic disease.

Overview Social Constructivist Research Approach. Ethnography is both the result of research and the process of research. Ethnography can generate or build on theories grounded in the views and perspectives of the research participants. Ethnographic research uses inductive processes to explore and explain the behaviors and beliefs that are a focus of the research. In this study, the constructivist perspective suggests that the research questions can best answered by the dialysis patients themselves. Their answers to open-ended questions and observations can reveal the social, political, cultural, and economic structures operating within the dialysis unit. (LeCompte & Schensal, 1999)

The problem of defining quality of life in chronic illness is complex. Narrative accounts can provide researchers with personal accounts that can help them better understand the multiple realities and perspectives of patient lives. Ethnography can offer the researcher a mechanism to become familiar with the perceptions, beliefs, and values that impact patient quality of life. Ethnographic study can provide the researcher a rich

picture of the multiple perspectives held by chronic illness patients. (Schensal & LeCompte, 1999)

Ethnographic research fits well into an interpretative paradigm that proposes reality is created in an ongoing interactive process of sharing and negotiating meanings. Reality is based in a cognitive construct, what we think; and reality is based in an affective construct, what we feel. In ethnography, because meanings are created and re-created through an interactive process, authentic understanding involves the researcher and the participants as equals minimizing the power differential as much as possible. (Schensal & LeCompte, 1999)

Once a problem is identified and the research questions are formulated, the next step is to situate the research within a grand theory, the research paradigm, and to identify a suitable method for conducting research. Ethnographic research uses participant observation and in-depth interviews to develop deeper understanding. I collected subjective patient quality of life on hemodialysis. I used analysis of data gathered from twenty participant interviews, participant observations, and inductive inquiry techniques. Data analysis was ongoing. During the process of research and data analysis, I constantly compared new data with previously collected data in order to generate new areas of questioning which I then explored during subsequent data collection and analysis. This iterative process allowed properties and dimensions of concepts to be identified. I then examined the data for relationships among concepts. Discovered relationships were then grouped into categories and sub-categories.

Interpretative and Social Work Paradigms: Their Intersection in Chronic Illness Research Interviewing. All research can be viewed as ideologically based

inquiry. In any study, the focus of inquiry is framed by the paradigm that the researcher chooses to approach the research question. Research findings are interpreted and imbued with meaning by the dominant theory guiding the research. The researcher must be clear about the theory being used and the implications that holds for the study question, data collection, fieldwork, and analysis. Every paradigm has its own internal logic and assumptions which make sense of the study and its results.

Social work research acknowledges the strengths of both quantitative and qualitative research. Quantitative surveys and experiments identify and refine health-related information. Problems can exist, however, if attempting to use numerical formulas to represent abstract health concepts, i.e. a 1 to 5 scale where 1 is defined as *definitely agree* and 5 defined as *definitely disagree*. The lack of an actual value for numbers in a scale is problematic for research. The distance between numbers, undefined in many surveys, hold no intrinsic meaning and so responses may vary between respondents. Even when paired with adjectives or descriptive response cues, the same differences can exist between respondents since people use and understand language in different ways. The quantitative approach to questioning research respondents can hold power asymmetries within patient self-report measures. The language chosen for surveys can act to limit and control information available for participant disclosure creating responses framed by the researcher's choices. The researcher is in charge of the study focus and determines question content. Any researcher bias may be obscured to respondents and consumers of the research alike.

In order to get at the qualities people use to define and think about chronic disease, qualitative research uses tools that are capable of measuring subjective

responses. Judgments are made by participants while answering questions in qualitative research. It is that intricate process of judgment which helps express opinions on indicators of health and quality of life. Individual judgments and their impact on responses might not be fully appreciated by the researcher. It is these judgments and their attached meanings that provide the context within which patients answer requests for information.

Ethnographic research uses naturalistic observation and backs up researcher observations with rich description from in-depth interviews. Field notes can be treated as texts open to deconstruction and reconstruction during the data analysis process. In-depth interviews can explore the socially and culturally constructed world of patients with chronic illness by capturing their own voice in their own words. This is an important juncture of constructivism and social work interviewing. Quantitative surveys offer inherently restrictive questions and response options. Open-ended interviewing removes the restrictions and opens up questioning to individual subjective perspectives on illness.

Using discourse analysis, the language people use, can give interviewers information about any bias in language uses to describe the body, health, disease, and illness. Discourse analysis can also look for potential distortions or underlying ideologies in questions and responses. Transcriptions of illness narratives can be analyzed for meanings and provide the subjective voices of respondents.

Quality of life lacks objective physical indicators. Even functional indicators might miss a true definition of perceived reality for chronic illness patients. Many paradigms can provide research applications relevant to the study of health and health

care policy. Interpretative interview techniques provide a good fit for examining the experience of chronic illness. Clinical interview training has its roots in the interpretative paradigm of constructed reality. The researcher or clinical interviewer recognizes that the content of the interview is contextualized for both the interviewer and the interview subject. Internal constructs, either overt or covert, are present for both interviewer and subject. Interview content is not expected to be stable to person, place, intent, or time; rather it is negotiated or co-constructed by interviewer and subject.

The content of any interview contains the internal and external worlds of the participants. Meanings can be kept separate or shared by either participant. In this paradigm, the respondent takes an active role in constructing the interview and is not just a passive answerer questions crafted by the interviewer. Internal representations are constructed through complex social, psychological, and cultural interactions. Interviews offer the interviewer privileged access to the subject's personal experience and meanings. The co-creation of content is accepted and should be made understood in a clinical interview. Social work interviewing uses open-ended questions and follow-up reflection to elicit narratives. Subjects are allowed to complete his narrative without interruption. The completed story can then be examined for meanings and placed in context. Reflecting back to the subject serves a summative function to make clear meanings not brought openly into the interview. Reflection also checks for interviewer bias. Follow-up questions or probes assist subject focus on specific aspects of the interview. Follow-up questions can also direct the focus to wider themes. This constant reflection mirrors the member-checking function of qualitative research data analysis. Deconstruction and reconstruction of interview content allows for clinical attention to be paid to short

interview extracts as well as the text of the complete interview. Clinical notes become formal texts and include psychological and physical characterization. Interviewer notes can include the subject's historical context, appearance, affect, and orientation.

The shared characteristics of the interpretative interview and the clinical social work interview are pluralism, subjectivity, and the social construction of knowledge and meaning. Transference and counter-transference are acknowledged as a part of the interviewer-subject construction of meaning. Pluralism gives the interviewer the flexibility to appreciate the existence of multiple realities and uniquely contextualized meanings rather than pursuing one objective truth. Clinical social interviewing and interpretive research interviewing agree to a social construction of knowledge reinforced through language. Discourse available for analysis by the social worker or interpretative researcher includes interviews, field/contact notes, and fully transcribed texts. The beliefs and techniques of interpretative research and social work research align in exploring health-related quality of life. (Mishler, 1985; Hertlein, Lambert-Shute & Benson, 2004; Nettleton, 2006; Smith, 2003; Creswell, 2003)

Research Ethics. The design of this study is ethnographic in nature and is framed in an interpretative, constructionist paradigm. The research techniques are appropriate to that research methodology. Approval for this study has been granted by the Institutional Review Board of the University of Montana and the Joint Institutional Review Board of Saint Patrick Hospital and Health Sciences Center. Each participant was invited by letter to participate in this study. Informed consent was obtained from each participant. Names and all identifying data is kept separately from interviews through a

coding system which allowed return to participants for follow up data. All data is kept in locked files.

Research Setting. The research was conducted in a moderately-sized town in the Northwest. The participants were receiving hemodialysis at a local dialysis center. Access to this setting and population was facilitated by the researcher's affiliation with the dialysis center as a clinical nephrology social worker. Data was collected at locations and times convenient for the participants. Interviews were conducted at chair-side during dialysis or at a location away from the dialysis floor that was identified as comfortable for the participant. (Morgan, 1997)

Participants. Purposive sampling was used in this study of the quality of life of dialysis-dependent end stage renal disease patients. The sample was initially limited to dialysis patients receiving therapy from a single nephrologist. Patients receiving therapy from a second nephrologist were interviewed during triangulation of data in order to verify data from the original participants. Application was made to both the Institutional Review Board of the University of Montana and the Joint Review Board of the community hospitals during the second year of research to add patients receiving dialysis therapy at the prescription of a second nephrologist. The study population was highly representative of the phenomenon being studied. At the time of this study, all participants were all over the age of twenty-one since the dialysis clinic did not offer treatment to pediatric patients. All participants had been on hemodialysis for at least eighteen months and are not actively pursuing renal transplant. Participants were chosen without regard to age, gender, socio-economic status, or disease etiology. I interviewed twenty patients during the study. Following precepts from Strauss and Corbin (1998), the

number of participants was determined by the point at which data saturation is reached. Saturation point is defined as the point at which no new data emerges from the interviews. I feel that the theoretical categories are richly developed, and categorical relationships are established. I interviewed fifteen patients in depth. One patient who fell into the study parameters declined to participate in the study. The study population includes three patients who initiated dialysis at the research site and subsequently moved to a satellite clinic affiliated with the research site dialysis unit are interviewed. Five patients of the second nephrologist are interviewed to check the general consistency of data from the first participants' interviews. Saturation was reached at this point.

I recruited participants through personal researcher contact. Confidentiality was assured and its limits discussed, especially as to the inability of the researcher to guarantee anonymity. Participants included information during interviews as to age, family configuration, time on dialysis, past transplant history, and the disease etiology that resulted in kidney failure at their discretion. I did not review patient's medical records and gathered no information from protected medical charts. The dialysis unit is the only one in the area and the number of patients varies. Due to the high possibility of participants being identified by others in the community, the study includes very limited biographies. I hope this doesn't make it difficult for the reader to follow quotes, but, in consultation with the participating nephrologists and the Internal Review Boards, this is a deliberate choice made in reporting the study results.

Research Instruments

Informed Consent. Each potential participant received introductory letter. It introduces the study, the researcher, and qualifications for participation. A request is

made for the patient to participate in the study and the letter contains instructions for contacting the researcher in order to participate. Patients who agree to participate are given consent forms for signatures. The informed consent forms begin with a brief description of the general purpose of the study as well as protections of participants during the study.

Participants are asked at the end of each interview if there were any information which should be excluded from written analysis and this is included in field notes. Participants are offered the opportunity to exclude quotes when findings are presented. Assurance is given to each participant that responses and transcriptions will be kept secure to insure confidentiality. The procedure for audio-taping the interviews is explained in the consent and a separate consent form is obtained for audio-taping. Explanation is given for alternatives to audio-taping if the patient preferred. Two patients did express this preference. (Pope & Mays Ed. 2006)

Role of Researcher

I selected a research paradigm for this study that I felt appropriate to the field situation and consonant with my own values and beliefs. The questions asked by the research and the analysis of research data all reflect the orientation of the researcher. (LeCompte, et al., 1999) My philosophical orientation is interpretive and constructionist. The choice of qualitative research techniques to explore quality of life as it is perceived by the patient reflects this constructionist orientation. Interpretivist research is transparent in addressing the inherent subjectivity and interpretation of all interviews and the researcher.

I am a Licensed Clinical Social Worker with a Master's Degree in social work, and have practiced as a medical social worker for seventeen years and as a dialysis-based renal social worker for nine years. I am also a trained forensic interviewer. I offer this as evidence of a clinical level of expertise in the psychological and medical issues impacting chronic disease patients. My clinical preparation as a social worker and clinical practice as a therapist and my own world view influence this study, research questions, and analysis. A key concern arises from the researcher's dual roles as social worker in the dialysis unit which serves as the research site and as the study researcher. This dual role positions the researcher as an insider and provides a key entrance to participants in the study. It also brings to the research someone trained to be a good listener and a reliable observer able to closely document what is heard and observed. As a social worker I am already positioned in the field as a learner, expecting the patient to be a self-expert, which facilitates building a strong, reliable partnership between the researcher and participant. Information communicated by a participant to the researcher is dependent on the situation and I discussed the social worker-patient relationship is discussed with every participant so that they could be sure that my role as a researcher wouldn't impinge on my willingness to help them in my role as nephrology social worker.

Adding the role of researcher to my role as a clinical social worker brings a an enhanced set of responsibilities, obligations, and privilege. A dialysis social worker brings to quality of life research a set of experiences and views regarding renal replacement therapy, its initiation, maintenance, and withdrawal. Because value orientations underlie philosophy, I have made every effort to identify, make transparent, and instill an aggressive analysis of researcher background and its impact on study

findings. Self-reflection is an integral part of social work clinical training and an important skill set when brought to the research role. As a clinical social worker, the reflective separation of self from patient is a constantly honed skill and supported by constant peer supervision of practice. Establishing and illuminating my position and world view both to participants in this project and consumers of this research throughout the project enhances the credibility of the findings and allows readers to understand how the project fits with and is influenced by my professional role as a social worker. I remained vigilant to concerns that, despite my clinical skills, I might be too close to participants to remain a neutral researcher. (Bailey,2007; Strauss & Corbin, 1998; LeCompte et al. 1999)

Participant Observation

The role of participant observer is integral to both clinical work and ethnographic research. Several levels of observation were in play at all times during the research project. I observed the patient and patient interactions with other patients and staff during the study. During the fifteen months of field work, another layer of participant-observer came into play as I added the researcher role to my social work role. During the research, I took care to make this dynamic as transparent as possible to the patients who agree to participate in the research. During my observations and interactions, I added another layer of self-reflection as researcher my already existing professional self-reflection. As the dialysis social worker, I had open access to all areas of the dialysis unit. This access included access to protected health information, staff perceptions of patients, and patient care conferences. Only information given during interviews and observation of patients is included in analysis for this study.

Interviews

During the initial interview, each participant first completed a version of the Cantril Self Anchoring Striving Scale. Cantril's Scale is chosen because of its ability to collect comparable data without imposing culturally specific standards or researcher expectations. Research utilizing subjective measures such as a self-anchoring scale to assess quality of life automatically includes individual, social, and cultural factors in the analysis. Compos and Thompson set criteria for a quality of life research method: flexibility allowing use in a variety of situations and a broad applicability to diverse areas of medicine. (Spilker, Ed. 1990) The Cantril Scale meets these criteria.

The Cantril Scale is a simple, widely applicable tool for illuminating the unique reality of each participant. The Scale has been translated into 26 different languages and has a reliability coefficient of 0.95. The Cantril Self-Anchoring Striving Scale is based on a model of a ladder with ten rungs. The top rung represents the "best possible" and the bottom rung represents the "worst possible", the Scale can be used for both research and medical practice. (Spilker, 1990) I asked each participant to place themselves on the appropriate rung of the ladder if the top rung is the best possible quality of life and the bottom rung the worst imaginable quality of life. I then asked why the participant placed him or herself on that rung. This was followed with an invitation to each participant to offer a narrative about his or her quality of life on dialysis.

The interviews were semi-constructed beginning with broad open-ended questions asking respondents to give first-person accounts describing their quality of life. Inviting personal narratives explores how each patient makes sense or meaning of their chronic illness and its meaning and impact on their lives. Autobiographical narratives are more

than information storage. Such narratives helped the interviewees structure their perceptions, experiences, and memories and allowed them to control the story and determine what to include and what to leave out. Patients whose lives were disrupted by chronic illness reconstructed a coherent self through the stories they told. This coherent self must accommodate the roles society constructs for the individual both before and after diagnosis. The participant, rather than the researcher, defines the meaning of “best” and “worst” in order to prevent intrusion of researcher definitions. (Bailey, 2007)

I followed up initial broad questions with questions designed to clarify or probe responses. My probing questions use as much as possible the respondent’s own words, i.e. “Tell me more about...” or “Can you help me understand...” (Riessman, 1993) The choice of probative questions is guided by the work of Boswell, et al. (2004) with congestive heart failure patients. Their work identifies five domains of quality of life: symptoms, role loss, affective response, coping and compensation, and social support. Their research identifies several illness themes including cognitive functioning, affective responses to anticipatory concerns about future quality of life issues, positive attributions about changes demanded by adaptation to chronic disease, and strong normalization coping strategies.

I digitally recorded all interviews. Audio taping was chosen rather than videotaping due to its easy portability and increased confidentiality of participants, which could not be offered with video recording. Audio tapes also allowed the interviewer to dispense with note taking during the interview. The exception was during the interviews when participants elected not to be audio taped. Although not capturing the non-verbal content of interviews, audio taping helps to preserve the sound of language. I used field

notes immediately after interviews to describe body language and non-verbal communications such as rolled eyes, shrugs, etc. Linking audio tapes, field notes, and transcriptions provides me with the ability to study each interview as an integrated piece and as data segments. This approach best met my concerns about fragmenting interviews into distinct segments and thereby losing meaning. (Reissmann, 1993)

The length of each initial interview was from one hour to nearly two hours. Subsequent interviews focused on gaps in data and reaching saturation. They vary in length and allowed me to ask for continuation of narrative where gaps occurred. This technique for data collection allows for an evolving model through constant comparative data analysis. Constant comparison of interview data allows for clarification of information presented in initial interviews and helps elaborate on emerging categories and relationships. (Bailey, 2007; Feldman, 1995; Morgan, 1997; Pope & Mays, Ed. 2006; Strauss & Corbin, 1998)

At the conclusion of each interview, I listened to each audio-tape in order to verify an acceptable tape quality. I made a second audio-tape as a back up during each interview. This immediate, rather than remote, review of the tapes helped in identification of ideas and concepts which could be of value in subsequent interviews. Immediate review of the taped conversation also allowed clarification of questions while the interview was fresh in the minds of the participant and the interviewer. I transcribed the interviews is from the audio-tapes. I constantly compared the interview tapes with the transcripts in order to grasp as closely as possible the participant's representation of quality of life. (Bailey, 2007; Strauss & Corbin, 1998)

Variations in speech patterns, including pauses, partially completed words, preservations, level of volume and intensity, etc. are included in the transcripts due to the richness such information imparts to data analysis. I edited out my probes and comments from the transcribed interviews to facilitate an unimpeded emerging quality of life narrative. Transcripts were coded by number and identifying information was deleted. Access to the tapes and typed transcriptions is limited to the researcher. I maintain the tapes and transcriptions in a separate locked file away from the participant's identifying data. Maintaining a mechanism to link transcripts to individual respondents enables contact for subsequent interviews and member checking as analysis progresses. Data is stored on a secure flash-drive which is kept in a locked cabinet. I made two paper copies of transcriptions. One is used for backup and the second is used for coding data.

Procedures for Analysis Coding and Memoing

Constant comparative analysis methodology uses coding and memoing as central components to analyze data looking for similarities and differences which can inform inferences. Open coding opens the data in order to allow individual categories to be identified. Open coding proceeds with a line-by-line analysis of each transcript. Axial coding reassembles the opened data into principal concepts then into subcategories. I then use elective coding then to develop relationships between categories allowing me to identify and explore patient perceptions of quality of life. The final coding step is to reintegrate the data categories into a framework capable of attaching meaning and significance to the patterns and connections of data. (Schensul, et al., 1999)

I begin memoing with inscription of mental notes. These mental "notes" include subjective and objective material. Subjective inscription includes my perceptions of

patients and the dialysis environment and reflects my conceptualizations of health and illness. Objective inscription includes notes of descriptive information about the dialysis environment, how space is configured, and where interactions occur. These initial mental notes as well as subsequent inscriptions are incorporated into physical memos which documented conceptual ideas generated from analysis of the data. (LeCompte & Schensul, 1999)

Memos helped me to cluster concepts, develop categories, and generate ongoing and often changing themes. Many memos also reflected how the evolving data ties back to the literature. I went back to the literature to find similar and contrasting explanations of emerging themes. Continuous memoing helped me to track data, develop categories, and possible follow-up questions, modify interview questions, uncover potential relationships between narrative segments, method decisions, and make analytical comparisons. It was during this process that I identified other populations and contexts not a part of this research project as potential future research areas. (Bailey, 2007; Strauss & Corbin, 1998)

My memoing and coding continued, and followed emerging patterns in patient declarations, frequency of occurrence, omissions, similarities and dissimilarities in interview responses, co-occurrence of information in responses, sequencing, and congruence between respondent perceptions. I continued coding until my analysis no longer uncovered new themes.

Mapping

Concept mapping provides researchers with a sense of the sociographic space in which the research occurs. Mapping helped me early on with a definition of important

physical study boundaries. In this research, the primary spatial data included the physical layout of the unit and the dialysis service/use area. Natural and man-made physical dimensions of the research area can be a major factor in understanding participant activities. Mapping allowed a clearer understanding of the configuration of socially constructed space and helped by to better document where patient interaction occurs. (Schensul, et al., 1999)

Measures to Enhance Data Quality, Trustworthiness, and Applicability

This section explains the measures used to establish the data quality, trustworthiness, and applicability of this study. One of the main threats to data quality was related to the duration of the field research phase. The dialysis unit and its patients lacked stability over time. Patients who were initial respondents died during the field work time, which to some extent, limited my ability to reconfirm my analysis through member checking. By the time of this final writing, eleven of the original fifteen participants have died. Over the fifteen months of field research, new members of the community under study entered the project parameters of receiving dialysis treatment for eighteen months or longer, but were not added as participants. (Strauss & Corbin, 1998)

Strategies employed to establish credibility, dependability, confirmability, and transferability included peer debriefing, negative case analysis, member checking, triangulating in-depth interviews with participant observation, and constant comparison methodology. Peer debriefing occurred primarily with members of my doctoral committee and most specifically with its chair; it covered emerging findings. I used negative case analysis to look closely at findings from one participant which did not support findings from other participants. Member checking occurred throughout the study

as emerging findings were brought back to participants to check accuracy. Information given during in-depth interviews is triangulated with my observations to check accuracy. All information is constantly compared during the study with other information in order to establish their credibility and dependability. Phenomena in this study of perceived quality of life are context dependent and subject to multiple interpretations. Findings may be transferable to other contexts, i.e. other dialysis unit populations or other chronic illness diagnoses. (Bailey, 2007; Cresswell, 1998; Strauss & Corbin, 1998)

My thorough documentation of study procedures and transparency regarding sample selection, data collection, analysis, researcher role, researcher orientation, and an auditable trail enhance the dependability of the findings presented in following chapters. Transparency of study's purpose, my purpose as the researcher, the research process, and rationale provides the reader with a sense that the study conclusions are dependable. When these are coupled with data providing rich description, the study can enable others to see how I reached my conclusions and allow them to make their own conclusions. (Cresswell, 1998; Strauss & Corbin, 1998)

Summary

The project is an ethnographic research study of end stage renal disease patient self-defined quality of life. I employed a social constructionist paradigm and an ethnographic approach in which I conducted observations and in-depth interviews with twenty end stage renal disease patients being treated at one renal disease unit in the Northwestern US. As the previous discussion has indicated, I am a credible researcher for the study. The findings are as accurate and dependable as possible, and results, while not

generalizable to the broader population, results may be transferable to similar populations.

Chapter Four

Research Results

The purpose of this study is to generate a substantive understanding of quality of life for end stage renal disease patients dependent on hemodialysis. The researcher first asked patients to rank their quality of life on the Cantril Self Ranking Scale. The researcher then conducted in-depth interviews with patients who had been on dialysis at least a year and a half and were not transplant candidates. Participants were asked follow-up questions as the emerging data dictated. To further a rich understanding of patient quality of life, the researcher spent two years doing field observations. Participant observations flesh out the description of hemodialysis dependent patient quality of life.

Contextual Factors

Study Setting—The Dialysis Unit. Ethnographic research focuses on a local population within broader geographic, socio-economic and political contexts. This study

took place in a dialysis unit in a small city in the Northwestern United States. The dialysis provider under study has more than forty years of experience with hemodialysis. Currently the dialysis unit provides treatment to about 120 patients.

Hemodialysis was originally a response to preventable renal failure deaths occurring in acute trauma cases. Initially the unit performed hemodialysis treatments as a joint effort with the local university. From 1959 to 1963, a total of thirty four patients received hemodialysis; twenty patients lived to discharge from the hospital. In 1966, two hemodialysis treatments were performed. In 1971 the first nephrologist opened a practice in the city in which this research was conducted. That year the unit gave one renal failure patient ten hemodialysis treatments. A major change in funding and therefore in access to hemodialysis treatment occurred in 1972 when the nation's Medicare End Stage Renal Disease program began. Under this program end stage renal disease patients could receive treatments largely paid for with public funds. Between 1972 and 1977 the unit performed 426 hemodialysis treatments. In contrast, 2010 the unit performed 12,032 hemodialysis treatments.

In 1999 and 2001, the hospital attempted to establish satellite hemodialysis units in two adjoining county seats. Each was approximately one hour distance from the study unit and the hope was to decrease patient travel time. The hospital satellites abandoned both satellites in 2004 due to financial and regulatory pressures on dialysis. However, a satellite unit remains in operation in a large town about two hours away from the study unit. The study unit meets or exceeds all governmental regulatory standards. A quality control process to maintain patient safety is active and a vital part of unit life.

Study Setting—City and State. The study is set in a small northwestern city and much of its service area is rural. The topography around the study area is fairly rugged and access to the study city may involve travel over mountain passes. The in-center hemodialysis program draws patients from a 150 mile radius covering five counties. Winters can be long and harsh, and the road conditions are often hazardous.

Politically, the state is conservative with a few liberal pockets. The study city is in one of the politically liberal pockets and has a state university. Much of the state is federally owned or is under state land management. Economics follows the state geography. Natural resource extraction industries have formed the traditional backbone of economic life. The research site's economy has been severely impacted with recent closures of mines, lumber mills, paper mills, and other businesses with a subsequent loss of adequately paying jobs. Many local jobs no longer offer health insurance. State income and educational levels consistently fall in the lower third of the nation. The state has a primarily Caucasian ethnic profile.

Study Setting—Catholic Hospital. The dialysis unit in this study is affiliated with a Catholic hospital and is influenced by its Catholic standards and ethics regarding medical care. For example, the hospital has relinquished obstetrics because birth control and sterilization are prohibited by Catholic ethics. The hospital also takes a firm stance against physician assisted suicide. This becomes a relevant point when discussing patient or health care representative decisions to withdraw from dialysis treatment. Withdrawal from dialysis is allowed by Catholic Church law as withdrawal from extraordinary treatment.

Economic Factors. As noted earlier, for most patients, dialysis payment is covered by Medicare at 80% of treatment costs. The state where the study is located subsidizes high risk health insurance for people who have health conditions which make them ineligible for most commercial health insurance. The Veterans Administration provides medical coverage for military veterans. The complicated federal-state Medicaid program provides public funds to pay for dialysis treatment for extremely low income patients. Private insurance plans provide primary insurance coverage during a thirty month coordination of benefits period, and Medicare is a secondary insurance provider until coverage reverses and Medicare becomes the primary payer. Without this complicated web of financial coverage, most patients would not be able to access renal replacement treatments which can cost up to \$3000 a treatment. The result is a significant investment of public finances in the treatment of renal failure.

Oversight. With this level of public investment and involvement comes intense oversight. Federal and state regulatory agencies provide oversight of dialysis providers. Medicare reimbursement rules dictate how much each dialysis unit will be paid per dialysis treatment, how many treatments will be covered, and ties physician payment to the number of monthly encounters with individual patients. Congressional regulations outline the conditions of participation for dialysis care providers. These regulations dictate staffing patterns, water quality parameters, dialysis specific medications, and facility specifications. Congressional regulations also mandate oversight through the End Stage Renal Disease Network, which provides dialysis outcome statistics to state governments, federal oversight entities, patients, and providers. State regulations also monitor dialysis providers and the state has its own quality audit systems in place.

Patient-Physician Relationships. In chronic illness settings, physician-patient relationships can extend over many years. In this study the average relationship with the physician was ten years. Decisions over treatment choices hold great potential for conflict. During many interviews participants discussed conflict with their physicians about treatment choices. This raised the question of autonomy within the relationship. Physician's goals and values can influence their medical recommendations. Patient acceptance or rejection of those recommendations is also based on their own personal goals and values and, possibly equally importantly, the patient's perception of the quality of the patient-provider relationship. In this study, dialysis patients expressed a greater expectation of intimacy with their physicians than that expressed by physicians during monthly dialysis patient care conferences. Eleven of the initial fifteen patients interviewed stated that they were viewed by the physician as "special" patients, that is patients whose welfare was vested with increased importance to the physician. As one woman stated, "I know it would break his heart if anything happened to me." One patient who was told by the physician that he could no longer dialysis outside of the intensive care unit shook his head. "I don't understand. He has always come up with one more miracle."

Patient expressions of disillusionment regarding their relationship with the physician seem to be rooted in this expectation of an intimate relationship. One participant stated longingly, "I don't think [the doctor] cares about me." As a male participant stated, "The doctors should be able to find out what's the matter. I just don't feel that they are trying." Another said, "The attitude. He wants me to die and get out of here." One man said his doctor personally blocked his transplant chances. "My doctor won't give me a kidney."

Illness Community Support Utilization Benefits. Another system to be considered is the illness community itself which holds an identity separate from that of the general community. Patient-to-patient interactions on the dialysis unit are complex. Fourteen of research participants in this study mentioned patient-to-patient relationships as important. One woman said, “They become like family.” “You get attached to the people you dialyze with. You get attached to them.” These informal interactions occurring within the illness community involved the anticipated benefits of formal support groups such as increased knowledge, empathy, predictions of the future, and emotional support. As one woman noted, “It helps to have people to talk to. You’re not the only one going through this.” At times, the illness community appeared to perform the functions of an affective family. One man described it as capable of “handling the shit”—the emotional and psychological burdens of chronic illness.

Patients stated they protected their legal families and general community friends from an emotional overload that could result in compassion fatigue. Respondents described families and friends as overwhelmed by the demands of chronic illness and no longer responding with needed help. “They’d rather have you tell them you’re doing good”, explained one man. Patients utilized illness community support particularly when handling news of a patient death or personal illness exacerbation. Patients discussed losses and fears among themselves, though I never observed patients talking to family members about such issues.

Patients also utilized the illness community to communicate illness specific knowledge, to produce protective illness myths, and give responses to personal health crises. Patients never related outside interactions with other dialysis patients to this

researcher. The intimacy of the members of the illness community seemed to end at the dialysis unit door.

Physical Context of Dialysis. The first patient arrives for dialysis treatment at about 6:30 a.m. when the still dark parking lot begins to fill with cars and paratransit vans. Patients enter into a medical waiting room. Some walk freely. Some rely on canes or walkers for balance. Others come in wheelchairs propelled by drivers or caregivers.

In rural areas, such as the one this unit serves, geography is an enormous challenge. Patients travel over mountain passes and often deal with icy and snowy roads. The nearest hemodialysis unit is a small six chair satellite 120 miles away which rarely has space to accommodate other than their residential hemodialysis patients. Traveling an average of sixty miles each way often presents an insurmountable difficulty and many patients find it necessary to leave extended family, friends, and homes to relocate nearer to dialysis and public transportation. Local housing costs nearer dialysis, however, can be more than double what patients are accustomed to paying. One patient said that he paid under \$500 for his apartment one hour from the dialysis city. A comparable rental he had seen in the city was \$1200. Relocation can also cause conflict within a family when other members are reluctant to leave everything behind. The children in one family implored the patient to remain in the family home and so nearer children, grandchildren, and his life-long community. The conflict is more poignant when the dialysis patient has a poor prognosis for survival over a year.

As gas prices rise and automobile maintenance costs become apparent, patients and families can easily fall into financial crisis. This crisis, although considered indirect to treatment for chronic illness, can debilitate the family as both personal and external

resources are exhausted. Five of the original fifteen participants relied on family members and friends to drive them to dialysis, requiring not only driving costs but also availability of drivers. Every research respondent living out of city limits mentioned transportation as a notable and difficult issue in maintaining dialysis treatments.

The arrival sequence is always the same—come in, weigh, and take a seat until a nurse or technician calls each patient's name. Then patients are led to the treatment areas. Patient treatments are staggered so that two patients are initiated on treatment at a time, approximately every 15 to 20 minutes—a schedule staff describes as grueling. The building is L-shaped with two wings of treatment chairs branching off a central office/waiting area. Computerized dialysis machines are present at each of twenty-four stations. They are programmed to deliver hemodialysis, monitor heart rate, blood pressure, and body temperature. They provide information to an average of eight on-site trained nurses and technicians.

Chairs are situated close together for economy of space and to enable to protect patient safety through close observation. This proximity means that patient privacy is at a minimum. At each station the dialysis machine is spotlighted to make cannulation, needle placement, easier for the nurse or technician who initiates dialysis treatments. A side table holds a treatment packet wrapped in a blue pad and containing needles, topical anesthetic, topical antiseptic, and tape. Nurses and technicians wear protective gear in case of blood contamination, white, fluid-impermeable coats, face masks, fluid shields, and disposable gloves. The cheerful banter by dialysis staff designed to comfort and distract patients does not mask the life saving purpose of dialysis—medical therapy intended to replace failed renal function.

Waiting for the call to treatment, patients check in with each other. They talk about weight gains, trips to the ER, and how treatments are going. When someone is called to the treatment area, you can hear “Have a good run”. It’s a benediction that rarely comes from a staff member. It is almost exclusively heard patient to patient. “Have a good run”. It is a simple phrase and to the outsider no more than “Have a nice day”. But this isn’t empty speech. Patients tell me that this simple phrase acknowledges the fear, the pain, the dangerous complications, and loss of control inherent in dialysis therapy. A good run means a run without hypotension bringing nausea, vomiting, cold sweats, ringing ears, blurred vision, or a loss of consciousness. Easy cannulation without unusually painful or difficult needle placement in the dialysis access is part of the good run wish. Every patient knows that each run can be good or disastrous.

Trauma occurred nearly daily on the dialysis floor. Patients were observed in varying states of dissociation when they witnessed a life threatening cardiovascular event during dialysis, or when they witnessed another patient vomiting, enduring muscle cramps, or losing consciousness. This dissociative response to trauma seemed to increase as the number of months or years on hemodialysis increased. For instance, one patient who had recently initiated dialysis treatments described asking a nurse to attend to another patient “who was worse off” but said that she felt rebuffed in her attempts. This patient described a gradual “turning off” of her response to the pain of others. Other, longer term, patients were observed exhibiting early responses i.e. increased respirations and a quick rise in pulse, then settling into a relaxed physical posture. For patients, blocking reaction to the distress of other patients within the illness community acted as a strategy to cope with trauma. Patients evidenced a distinct lack of expected reactive distress,

continuing to watch television, for example, when a patient four feet away was vomiting or became unresponsive and lost consciousness. This dissociation occurred even when the person suffering was well known to the observing patient. An even more rigidly organized dissociative psychological defense state was observed to be in place when another patient experienced a life threatening cardiopulmonary event during dialysis.

Patients on the dialysis floor typically see and/or hear what is occurring with other patients. Patients are tethered to the dialysis machine by less than six feet of blood tubing. They are effectively immobilized and are unable to physically escape proximity when others vomit, or cry out in pain, or when a code is called. Even in the face of another patient's death on the dialysis floor, patients must finish their dialysis run, which can prolong exposure and delay escape for hours. Patients witness the suffering of others and can neither come to their aid nor flee.

When a code, response to a life threatening cardiopulmonary event, is run for a patient at the dialysis unit, hospital security personnel, ambulance crews, and fire department paramedics all respond. When curtains are available and don't present an impediment to medical interventions, they are pulled to give some privacy. But curtains only obscure vision and do not mask the sounds of a code. Curtains cannot obscure the sound of nurses calling the patient's name in an initial attempt to arouse him, or the zap of a defibrillator, or the counts of cardio-pulmonary resuscitation. Several patients who were initially interviewed described routinely undergoing primary and secondary trauma during dialysis. All patients in subsequent interviews had either witnessed or personally experienced physical and emotional trauma. Imagine for a moment, looking around your workplace, church, or classroom that one in five would die in the next year—and you

might be one of the five. And if you survive for a five-year span, the statistical chance of death rises to three in five. Patients undergo acute-on-chronic trauma, which may be compounded by previous or ongoing trauma from co-morbid disease states—diabetes, cardiac disease, genetic diseases, cancer, vascular disease, and the unresolved knowledge of not knowing the etiology of renal failure.

Acute loss is not the only loss endured by dialysis patients. Cumulative loss occurs over time for dialysis patients. The one year mortality rate for dialysis patients treated in the United States is 25%. (End Stage Renal Disease Region 16 Statistics 2008) This means that statistically one in four new dialysis patients will not live out their first year on dialysis. That figure rises dramatically with a mortality rate at five years on dialysis of 60%. (End Stage Renal Disease Region 16 Statistics 2008) The average annual mortality rate for dialysis patients nationwide is 24%. In this unit, the mortality rate hovers between 20% and 24%. (End Stage Renal Disease Region 16 Statistics)

Hemodialysis—a Rigorous Treatment Choice. A comprehension of the rigors of hemodialysis as a treatment for renal failure made me seek an understanding of the lived realities of patient life on dialysis. Most people start discussions of medical advance directives with a bald statement. “I just don’t want to live on a machine!” This study was grounded in the question of what makes men and women on dialysis choose just that—life dependent on a machine. Just fifty years ago end stage renal disease would have been a death sentence. Today sustaining life after renal failure is medically possible. For every participant in this study staying alive is accomplished only through reliance on mechanical intervention to replace failed renal function. One woman

describes the terrible effect of reliance on a machine in order to live. “I can’t enjoy my life. I gotta come back to this machine. This machine is keeping me alive.”

The ethic to be involved in meaningful work remains strong for many hemodialysis patients. Patients refer to dialysis as “the job” or “my dialysis career”. Initiating treatment is commonly called “being on the clock”. Non-dialysis days are “my day off” or “vacation”, the language of work may bridge and make entering the world of chronic illness more acceptable to patients.

Foreseeable Consequences. Some participants face the heartbreak of knowing that the cause of their renal failure is inheritable and might be a part of the futures of children and grandchildren. Chronic diseases like polycystic kidney disease can attack members of multiple generations. Others patients face renal failure occurring as a secondary issue related to another devastating disease such as diabetes. Diabetes can steal childhood and adolescence, interrupting critical developmental stages for both patient and family. Blindness, neuropathy, paralysis of the gastrointestinal system, and amputations can be a part of the illness landscape before or after diabetes impacts renal function. For other participants, the cause of renal failure is more acute, following cardiac catheterization perhaps. Regardless of the cause of end stage renal disease, the resultant kidney failure can be devastating. All study participants accepted life dependent on a machine. Four study participants lost their struggle during this project and are no longer among us. Eleven of the original fifteen died between the start of the study and this writing.

One patient had polycystic kidney disease which is genetic and often impacts many members of a family. One woman described seeing her sister’s health deteriorate over

several years also due to diabetes and kidney failure. “I watched my sister die. It was horrible.” This woman was always aware that she shared the diagnosis. “It was scary. [Long pause] Knowing my day would come.” She later shared her fears for her children and their futures.

Participant Demographics. A composite demographic for participants in this study mirrors many aspects of the larger societal demographics as recorded in the 2000 United States Census. The gender split is nearly even. Eight participants were women and seven were men. Five participants defined themselves as strongly identified as part of a formal religion. Three claimed a strong spirituality but did not identify with a formal religious community. Seven participants expressed a broad but undifferentiated Christian belief system held by their family and the general society in the area.

The study population was representative of the state population. Education levels for study participants mirrored that of the state. Of the study participants, two had eighth grade educations, two had their high school equivalence degree, one graduated from a private college in state, and the rest were high school graduates. Four of those interviewed were born out of the state. All other participants were born and reared within the state. The dialysis service area encompasses a large Native American Reservation. The United States Census concluded that approximately 10% of the state residents are Native Americans. The study population had two Native American participants; the remainder of the study population was white. There were no other ethnicities represented. Both Native American participants self-identified with both the larger Native American culture and with their individual Tribal cultures. Study participants were about

evenly split between married and single. Seven of the study participants were currently married. Three of the married couples had been married for more than fifty years.

Spousal Support. The three participants who were married for over fifty years were also the three participants who described their spouses as very supportive and their marriages as very happy. “My wife is my best friend.” “I don’t know what I would do without him. He takes care of everything in my life.” They all spoke of “the ups and downs in every marriage” and talked about feeling confident that their children would provide support to their spouses “when the time comes”. One of the married participants had been widowed and was remarried. She talked about the uneven nature of stress and commitment in blended families. One participant had been divorced twice and was currently married for the third time.

Two of the study participants described their marriages as highly conflicted and as not contributing to their welfare or negatively impacting patient quality of life. Both felt that financial concerns compelled what functional help their spouses offered. Both stated that emotional/affective support from their spouse was absent. One man who was no longer able to chop wood or feed the stock lamented, “If she would help with the chores...” Another man told about his wife’s resentment of his illness, “I know she thinks I should just die.” Both men had been in their marriages over 15 years and described a long history of conflict not only with their spouses but also with their children. Conflict did not seem to appear in all domains for one patient, while the other reported ongoing conflict with health care providers and neighbors as well as his family.

Three participants were widowed. All three described their past marriages as happy and supportive relationships. They described experiencing loss of financial

support, loss of functional support, and the loss of emotional support upon the death of their spouses. This reported loss of spousal support was in sharp contrast to the level of support the participants reported providing during the illness and death of their former spouses. Participants said the loss of their spouse was accompanied with loss of pensions and social security amounts were decreased. For widowed participants support at medical appointments was no longer automatic and now involved a role change with necessary reliance on adult children. Physical and emotional intimacy and the intimate functional involvement of a marriage were gone. One woman said, “It would have been easier if only I had gone first.”

Three participants were divorced. The relationship narratives differed between widowed and divorced participants. Both groups reported similar support gaps, however divorced participants reported they felt less helplessness and more volitional control than did widowed participants. The divorced participants had not experienced the illness and death of a former partner or been expected to meet their support requirements during lingering illness. These divorced participants reported less reluctance to rely on children for support. The two participants who had never been married reported significant past domestic relationships, although neither one was currently in a relationship. None of the divorced or separated participants reported that their marriages or relationships had ended as a result of stressors related to chronic illness.

Age. Participant age ranges reflected their chronic illness status. Participant ages ranged from mid-40s to late 70s. This range is representative of the hemodialysis unit population in general. Six participants were between the ages of 70 and 80. Four

participants were between 60 and 70. Four participants were over the age of 50. Only one participant was under 50.

Paying for Treatment. All but one of the participants, regardless of age, had Medicare as their primary medical insurance. Three had state and federally funded Medicaid. One of those had Medicaid as her only insurance. One had Medicaid as a secondary insurance. For two participants, dialysis costs not covered by Medicare were covered by the hospital charity care program. Indian Health Services served only as tertiary insurance for the two Native Americans in the study. The great majority of direct hemodialysis-related medical costs were carried by public insurance. Indian Health Services paid for medicines not included in dialysis treatments for all tribally enrolled patients.

Indirect Treatment Costs. Participants all reported that indirect treatment costs such as medicine co-pays and travel costs were decisional issues. Co-pays for medicines alone can reach above \$500. One participant eventually lost his home when he could no longer afford both gasoline costs and mortgage payments. Only the two Native American patients did not mention travel costs. Those participants had access to Tribal transportation at no cost to the riders.

Thirteen of the study participants traveled in excess of one hour both to and from dialysis. Dialysis is both expensive and extremely technical. Treatment must be overseen by a physician who is an internist especially trained in nephrology as required by Medicare / Medicaid Conditions of Participation, thus dialysis centers must be located in a medical community capable of meeting the criteria. As a result, dialysis treatments

are not available in many smaller rural towns. Either long travel or dislocation from hometowns becomes necessary.

Co-Morbid Illness and Derivative Conditions. Chronic medical conditions primary to end stage renal disease are reflective of larger chronic disease statistics. Five patients were diagnosed with cardiovascular disease and high blood pressure. Seven patients were diagnosed with diabetes. One patient had autoimmune disease. One patient had polycystic kidney disease. Two patients had end stage renal disease secondary to a cancer diagnosis. Conditions derived from primary illness or dialysis itself mentioned by participants during the interviews were moderate to severe soft tissue calcification, chronic pulmonary disease, poor vision or blindness, non-renal failure related cancers, neuropathy, non-healing wounds, and limb amputations.

Quality of Life. When asked to rank their quality of life on dialysis using the Cantril Self Ranking Scale, nine of the participants, a majority, judged their quality of life at five or above on a scale of ten. One participant did not tie his quality of life to a rung on the ladder simply declaring his life as “above zero”. His reasoning was, “I’m moving and I’m not dead yet.”

Participant responses reflected the literature on chronic illness and quality of life. According to the literature, renal failure patients typically compare their quality of life on dialysis to either a pre-end stage renal disease state or to compare current quality of life to perceived states of others both on and off dialysis. In this study, the majority of participants judged their pre-illness states as more positive than quality of life states after chronic illness. Two participants felt that their quality of life improved after initiating dialysis. They described themselves as more worthwhile people after renal failure and

dialysis treatment. “I had no purpose. Now I’m seeing I have a purpose. [Dialysis] changed me.”

Dialysis patients described people who were not on dialysis as “much better off” than dialysis patients. One woman pointed out that people who do not have chronic illness fail to comprehend the differences in pre- and post-illness states. “They don’t even realize how good they’ve got it.” Self-comparison to other dialysis patients consistently reflected a sense of superior health. “At least I haven’t lost a leg.” “That’s the thing when I get down to it. They’re, ah shit! There are people a lot worse off than I am.” No one described themselves as having a lower quality of life than other patients. They did describe fear and anxiety for a health state deterioration for a future self. They could contemplate future health crises, including amputations and death based on another’s current health state.

Patients compared their quality of life to the quality of life they perceived for other patients in terms of functionality. “I can do things that a lot of people can’t do.” He went on to tell me he could drive, shop, walk the mall, read the paper, and live independently. One patient with diabetes made direct referral to other patients who had lost limbs to diabetic vascular disease. This was a constant source of fear of what might happen to them. “Thank God I’m not there yet.” Another expressed both gratitude and concern for others. “I’m not missing a leg. I still feel sorry for those [patients].”

Emotional Deterioration in Quality of Life. Participant responses described how their rating of their quality of life changed in devastating ways after initiation of hemodialysis. “Life changes dramatically. It’s tough. You don’t really have a life anymore.” Another reflected feeling constrained across all domains living life dependent

on hemodialysis. “You’re very limited in life.” Time spent on dialysis and ability to travel or plan independently were the most mentioned effects of dialysis. And another respondent referenced technology and stated bleakly, “In the back of my mind, I have a machine keeping me alive.” Yet another compared life pre- and post-renal failure. “I’ve worked three or four jobs my whole life. This sickness has taken everything from me.” For this man losing his work role was central to a greatly diminished quality of life. Another respondent expressed her ambivalence before the interview and her desire to be truthful. “I was hoping you weren’t coming here looking for something positive about dialysis. Because I truly think it’s inhumane. I can’t help it. I see us crying.” This is the woman who was distressed by the suffering of others during dialysis. Another described the difference in life before and after chronic illness. “I had a wonderful life. So now it’s my turn and—it’s just not a nice life.”

Members of the study population had all been on dialysis treatment for at least eighteen months, yet the differences between pre-and post-hemodialysis life remained stark. One man described dialysis as an ongoing trauma. “It’s been three years, and I’m still not used to it. It’s not something you want to get used to.” For one respondent, dialysis represented a complete loss of personal liberty. “I feel kind of trapped—like in prison.” And when asked is it worth it? He expressed his doubts. “Sometimes I wonder...[voice fades off].” With an eloquent shrug, this participant summed up the effect of chronic illness on all areas of his life. “It’s really made things tough.”

Do or Die. Respondents were asked why then did they start dialysis. The answers reflected a tension between valuing life and living with the realities of chronic illness and its treatment. One respondent expressed his gratitude for the time dialysis

treatment had given him. “Three years I wouldn’t have had.” Others echoed his sentiment of life. “I’m not pushing dirt.” For some the choice was clear. “If you don’t, you go to sleep and don’t wake up.” Another participant responded, “You got to do what you got to do. You can either accept it or quit.” For a third, “It’s what I have to go through just to stay alive.” One participant spoke not only to his own struggle, but also to the struggle of others. “It’s how much you value your life. Some people can’t do it.” For another respondent, it seemed the only choice. “I don’t give up because what else is there? What else is there?”

Others expressed ambivalence about their quality of life on dialysis. “Well, it keeps me alive. [long pause] At least I guess that’s what it does.” A second participant commented, “It’s keeping me alive. I just don’t like the way it’s keeping me alive.” And a third, “It’s a necessity. But it’s hard.” One man said, “There has to be something that makes you do it.” For some, that something is being able to continue parenting. The following respondent, a woman in her sixties, saw it as a choice between the rigors of treatment and being there able to continue interactions with her children. “I want to live for my children. Otherwise, I wouldn’t mess with it.” Another woman, also in her sixties, talked about the importance of living for her children, “They need mom and so I’m lasting as long as I can.” Both women were widowed and the needs they perceived in their children and how they valued being mothers eclipsed the fears and inconveniences of treatment.

For some participants, it was spirituality or religion that provided a main reason and meaning for continuing to pursue treatment. One man, a devout Catholic, said, “My church, my faith—it keeps me going.” Another man, who described himself as very

spiritual, but not subscribing to a formal religion, expressed hope for a better life beyond this one. “You have to believe there is something on the other side.” One participant believed in a greater power than his but had no specific conceptualization of what that would be. “I don’t have a name for it. I know there is something out there.” One woman felt that her chronic illness experience had a place within a larger plan God had for her life and the lives of others. “I’m here to appreciate whatever God gave me and maybe for others too.” One person also felt there was a deeper meaning to her illness. She quoted her pastor as saying that what happens in our lives “gives us a chance to learn or maybe to teach.”

Empathy. One man, who had been on dialysis over four years, talked about the toughness of required of patients who choose dialysis. “It’s hard to see people who are basically, not physically, but emotionally and mentally, tough and still they can’t fight the disease and all the complications that comes with it. It’s real hard.” One man who had been on dialysis for five years talked about the inevitable progression of end stage renal disease. He had watched many new patients begin dialysis and others die. “I feel sorry for the new ones. I see the others leave. We come and go. I make a joke, ‘We’re all dying to leave’.”

Compassion. Two thirds of the participants expressed compassion for other dialysis patients. “The other day she was crying, and I said [to the nurse] ‘I’m feeling good right now—you go to her’.” The same patient talked about her intense emotional response when other patients decided to stop dialysis. She described a mix of fear and compassion. “I walk into the waiting room and you know something’s going on and you think, ‘Somebody’s in the room upstairs [hospice].’ And you think, ‘Am I going to

suffer? How long is it going to take?” After a lengthy pause she continued. “How long is it going to take for me to die?”

One patient told the story of a waiting room conversation between patients. “We both said we are just tired. Right now, we are tired. We would kind of laugh and say, ‘Okay, which one of us is going to be first [to die]?’” She waited and then said softly. “I could hear in his voice that he was tired. He was fifty-two.” He was weary, yet he was younger than she. Some respondents described protecting the emotions of other patients by hiding their own struggles. “I don’t want anyone to see me depressed. I just like them to see everything is okay. Even if it’s not.” She was trying to give hope to others even when it eluded her.

The themes of shared grief and possibly a shared future surfaced in several interviews as patients described trying to comprehend the deaths of others and eventually their own deaths. “It’s really hard watching them [other patients] die one by one.” Patients share an intimate knowledge of chronic illness. “You get to know them. You know because they are in the same boat you are.” The precariousness of life emerged. “You put yourself in that same boat knowing something could go wrong and you wouldn’t be able to make it out [survive dialysis] another time.”

Family Ties. The quality of family relationships as a source of care giving was explored as critical to quality of life. The most intense level of home care giving for end stage renal disease patients came from spouses. This intense level of care giving was mentioned during interviews by all participants who were married thirty years or more and were perceived as strong. One patient talked about the emotional support he gained from his wife. “My wife is my best friend.” Another patient discussed functional care

giving. “My life is good because of my husband. He really takes over. Handles all my medicines and everything.” For two patients, the person perceived as providing strong support was no longer living. One woman told of considering discontinuing hemodialysis after her spouse died. “[My deceased husband] was so good to me. When he died, I wanted to go with him.” A second patient said his deceased wife remained a support to him after her death several years earlier. “I talk to her every day.”

Some patients recognized the toll care giving exacted from family. “My family is tired.” And for another man, “It’s all a huge burden to my wife. She does 95% of what I need.” For these patients, reliable care giving support was perceived as at risk. One man excused his wife’s unreliability as a caregiver. Though they remained married, they lived separate lives. “She’s got to go sometimes. Enjoy life, you know? I can’t go... I can’t enjoy it with her.” Others also expressed feelings of alienation from family. “I don’t feel like I belong [as part of the family] anymore. I mean, just like (pause) I’m not—oh, (long pause).” Another described isolation from family and friends who were unable to accept his chronic illness. “I’m alone anymore. I try to fit in but I can’t. Sometimes I wonder.” One man described his family nearing the point of compassion burnout. “The family is tired. They do everything for me now.”

Spiritual Support. Several patients described gaining support from their spiritual life. For some, organized religion provided needed support and emotional structure. One man who self-identified as a Catholic said, “My church, my faith, is important to me. It keeps me going.” One woman perceived her relationship with God as supportive during past crises and expected that support to continue to be there for her to lean on when necessary. “When it counted, God kept me healthy [when her husband

was ill].” For another woman, initiating dialysis fulfilled a covenant with God that she felt she had entered into through her religion. “God gave me life not to kill myself.” For other participants, spiritual support occurred without allegiance to any organized religion. They described another dimension of existence and in which they trusted to offer something better. One participant explained, “The basic thing that helps me be here...you have to believe that there is something better on the other side than this.” One man described his belief in the immutability of human personality and its eternal nature. “I don’t have a name for it. I know there is something out there. maybe it’s in the person themselves what they choose to believe.”

Support Provided within the Illness Community. Affective support from other patients was described as important during the interviews. One woman talked about the knowledge only other patients have. “It helps to have people to talk to. You’re not the only one going through this.” Support from other patients was described as meeting support needs that we might expect to be met by family members. For instance, one woman talked about the attachment family that develops within the dialysis unit. “You get attached to the people you dialyze with. Patients in [this unit] become like a family. They really count on other people.” One patient, in her fifties, was interviewed after she had transferred to a satellite dialysis unit. “I went in there hoping, with the attitude that it would be like [it was in the study unit], but soon I learned you needed to do things for yourself there.”

Providing emotional support to other patients gave some a reason to continue treatment. One participant said she came to dialysis to avoid discouraging other patients. “They keep me coming. There is a lot of good people here. That’s the thing when I get

down to it.” One patient spoke eloquently about drawing from each other the courage he felt was needed to face the demands of chronic illness and its treatment. “It’s in everybody. You know, everybody has that kind of courage. Nobody is better than anybody else. It’s inside all of us. Courage can be just coming here

Physical Deterioration of Quality of Life. Participants talked their decreased quality of life given the physical effects of dialysis. One woman described keeping everyone but her husband at a distance after dialysis to conceal its effects. “I have about two to three hours after dialysis when I’m really uncomfortable and agitated. So I have to plan for that.” For some, the accommodations left part of treatment days unaffected. Others found that post-dialysis effects were too profound to salvage any part of treatment days. “There are the days between dialysis that I do feel good. The day of dialysis...[slow negative shake of head].” For some participants, even the days between dialysis treatments became physically incapacitating.

Lines in the sand about when quality of life had deteriorated to an unacceptable level were drawn and redrawn as chronic illness progressed. One man acknowledged his progressive deterioration. He had been on dialysis for more than eight years and was aware that his health was deteriorating. “I’m just going downhill.” Many talked about the changing nature of their health status. One woman talked at length about her changing treatment decisions regarding what she would find an acceptable physical quality of life. “I have my limits and I say ‘I’m not getting my leg amputated’. I say ‘I am NOT going to. Um, but, you know. I keep saying I’m not going to do this much—I’m not going to do that much.’ [Voice trails off] A quality of life she found unacceptable at one point was one she could see herself accepting as her disease progressed. One man in his early

fifties would continue, he said, “Until I have a stroke or something. I don’t want anyone wiping my butt!” One woman described patient acceptance of progressively severe treatment choices as something to be expected. “Everyone says [they won’t lose a leg] and then when it comes to that, they do it.” She quoted an RN, “Everyone says [they won’t let them amputate their leg], but when it happens...”

Accepting Chronic Dialysis. End stage renal disease patients who exhibited the least psychological distress were also most likely to express a sense of accepting chronic disease as fate. Chronic disease was a simple fact of life. A gambling metaphor was part of the interview responses of two male respondents. The first often used terms related to gambling. “You gotta play the cards you're dealt.” He was adamant that a good gambler always makes the most of any hand he holds. A second man stated that he wasn’t putting life on hold waiting for good fortune. “If it wasn’t for bad luck, I wouldn’t have any luck.” One man angrily explained his chronic non-adherence as not a matter of his choice but instead a matter of physician choice. “Because they [the doctors] put me non-compliant, I might as well be.” A respondent described an acceptance of death as something nearly neutral. “My day is coming. No fears. No regrets.” The choice was simple and unadorned. “You either accept it or quit.”

Loss of Freedom. A common theme presented during the interviews was the loss of freedom. One man talked about his plans to retire with his wife. “We had really wanted to travel. Had a good pickup and good camper, and we were going.” For another respondent it was the daily freedom that was most important. “What I miss most in life? It’s driving and going where I want to go.” Spontaneous travel, for instance, to visit adult

children and grandchildren held great value and was mentioned in nearly every interview. “I could go any place I want to—without any preparation.”

Concerns about Funding. Uncertainty about the future emerged as a major thread of the interview responses. The interviews occurred during an economic downturn nationwide and participants expressed fears about whether the public would continue to fund dialysis. They were exquisitely aware that their lives were dependent on the will of the public. The media was full of rumors about health care reform. The rumors included the possible rationing of dialysis treatment through policies that links payment to outcomes. These outcomes could hinge on age or co-morbidities such as cardiac health or blood pressure. One patient was concerned about the future of his access to treatment. He was over the age of 65 when rumor had it that dialysis would be denied. “I’m really worried about this health reform business—afraid of rationing.” Another respondent was afraid of what impact health care might have whether or not she could continue dialysis treatments. She had cardiac disease, vascular disease, and her age was over 70. “I’m worried about our new, our medical care. I think it’ll make it worse.” One patient worried that physicians were already responding to limited Medicare financial compensation to doctors. He was afraid it had already resulted in decreased efforts by his physician to treat his illness.

Perceived Resilience. Respondents who rated their quality of life as good or better all described prior survival and resilience in their own lives. For one man renal disease and eventual dialysis treatment for renal failure were not the greatest challenges he had faced in life. “This isn’t the worst I’ve had to go through. There are a lot of worse things I’ve had to do than this.” Another man expressed confidence that he was prepared

by his past life to meet this current challenge. “I’ve had bad luck since I was six weeks old. I’m kinda used to it.” Despite his depiction of negative luck he continued to hope for a more positive future. “Well, turn the page to the next chapter and see if it’s better.”

The belief that whether to give up or to survive is a choice emerged consistently during interviews. One respondent made the choice clear. “You can go ahead and just give up and let everything go or you can just try and survive.” One woman said simply, “I’ll keep going because I am not a person who gives up. Especially on myself!” For one man the strength needed to meet the current demands of chronic illness didn’t differ from that required during a life of struggle. For him it was just a matter of choosing to work at survival. “I have always had a tough life as long as I can remember. Nothing came easy. Everything I have had to do I have had to work for.” Another respondent said of his past life. “It braced me for the life ahead.” One woman summed up her approach to life. “You can’t give up and be stronger and better.”

Patient and Health Care Providers. Patients often mentioned that provider-patient relationships discussed during the interviews were central to their experience of chronic illness. Several patients express deep frustration. They expected modern medicine to deliver a miracle. This frustration was directed at the physician rather than at the disease or its treatment. One woman lamented the progressive effects of the disease. “I wanted the doctor to do more for me.” One man spoke about his broken trust in medicine. “I don’t understand. Medicine has always had something.” The physician had become symbolic of hope for miracles, when one did not appear, the physician bore the blame.

One man moved from frustration to anger. He had been told he was not suitable for a renal transplant. The reason the transplant center had given him was his lack of adherence to treatment recommendations. He placed the blame on a physician conspiracy which had blocked him from receiving a transplant. “I started in [another town] and [the first nephrologist] said, ‘No compliance’. All the other doctors started to listen to him.” His lab results told another story and showed metabolic deficiencies. Another man described ongoing conversations with his physician about his non-adherence to the treatment plan. The patient missed approximately one-third of his prescribed dialysis. The physician had characterized this as slow suicide. The patient’s rage and feelings of abandonment turned on the physician. “The doctor he’s told me three times, ‘Why don’t you just stay home and die?’” He expressed his profound disappointment when his physician didn’t meet the patient’s expectations of support. “I don’t think that’s for a doctor to say.”

One woman described being frightened by physicians expressed conflicting plans for her treatment. “[The nephrologist and oncologist] had a big row the first—when they started treating me.” She characterized her oncologist as preferring aggressive and debilitating treatment, hoping not for a cure but wanting to fight for remission. Her nephrologist advocated a treatment plan that he felt would better balance the benefits to the patient in terms of quality of life and efficacy in treating the cancer. “[The oncologist] was so interested in the cancer that he had tunnel vision.” This patient felt that each physician interpreted the importance of patient quality of life from different perspectives. In the end she changed to another oncologist.

Autonomy and the issue of making fully informed decisions about treatment arose as a major theme both in initial and follow-up interviews. One man in his seventies and a strong Catholic, related a conversation with a friend regarding the patient's quality of life and his choice to continue or withdraw from dialysis treatments. This man defended his right to autonomy in making such a personal choice. He drew an analogy between disabilities acquired during a lifetime and disabilities diagnosed prenatally. "It's like arguing abortion when the baby is going to be born sick." He forcefully made the point that only the person living the life can truly judge its quality. "Maybe my life isn't great, but I'm the only one who can decide that."

One man expressed regret at making the decision to start dialysis without what he considered full information. He felt that his physician had not fully informed him of how his life would change. "If I'd known, if they had told me what it was like, I don't think I would have started. But now, [slowly shakes head]." He found himself in what he termed a Catch 22—unhappy with his quality of life on dialysis but unwilling to discontinue treatment and die. One man said that he thought he was rescued from end stage renal disease by modern medicine, but found himself still faced with tremendous health challenges. "I knew they were throwing me a life preserver. I didn't know they were going to drag me behind the boat."

Another respondent addressed differences in attitudes toward care. This conflict was between nursing staff and the physician. She described being told her understanding of patient rights to autonomy. "Before [the nephrologist] told me I could refuse a fistula and stay with a catheter, I felt like you had to do what they told you." Another participant described conflict with nursing staff at a previous unit. She felt that her requests for

information were seen as obtrusive by nurses. “Sometimes I wonder if I ask too many questions.” Issues of autonomy arose during another interview. “The doctor told me a few months ago, because I wasn’t doing good on dialysis, ‘I think you should quit.’ And I said, ‘I’m not ready to quit. I’ll know when it’s time’.”

Some patients felt that their physicians ignored patient autonomy by not disclosing the rigors of dialysis before they began treatments. One woman said she might have made different choices if she had known how difficult treatment for chronic disease would prove to be. “If I’d known, if they had told me what it was like, I don’t think I would have started.” One man saw his physicians’ unvarnished discussion of the patient’s certain death if he did not dialyze as coercive. And another man echoed the feeling that medical advice about choices after renal failure was coercive. “The doctor was making death threats.” In reality renal failure, not his nephrologist, threatened his life.

The issue of being fully informed before choosing health actions was central to one interview. This patient had renal failure secondary to polycystic kidney disease (PKD) which is a genetic disease. PKD impacted many members of her extended family. Three were on dialysis at the time of these interviews. She wondered if more comprehensive knowledge might have changed her decisions. “You know two of my kids are—have been diagnosed with PKD. So you know that bothers them—that this is what kind of life they have to look forward to. It’s overwhelming. If I’d really understood, I don’t think I would have taken such a chance having kids.” Now her focus is on teaching them to cope.

Summary

Respondents told the stories of how quality of life had changed for each of them when faced with an illness that could not be cured and lives that depended on machines. Respondent narratives described quality of life embedded within familial, social, geographic, financial, religious, governmental, and medical contexts. The next chapter will discuss researcher conclusions.

Chapter Five

Discussion and Conclusions

Introduction

This ethnographic study provides a better understanding of the quality of life for hemodialysis patients. This study utilized interviews and field observations over a period of fifteen months. End stage renal disease and its treatment can represent a severe threat to self perceptions and perceptions of the world. How a patient perceives quality of life in the context of chronic illness is unique to each individual. The questions for researchers studying quality of life become about not just the strategies each patient uses to cope with life with a chronic disease that can be treated but not cured, but also how each patient perceives his changed world. This new landscape determines how the patient perceives his quality of life. I organize the discussion of the study findings around the research questions.

What utility does life on dialysis hold for patients?

Life on dialysis gave patients the ability to choose life over relinquishing life. Regardless of how patients came to renal replacement therapy, they all faced major organ failure which, without treatment, would result in death. The complexities of that choice

reflect the challenges patients face with life on dialysis. As one participant stated it, “One life ends, and another life begins.” Several patients complained about the quality of information given to them by their nephrologist. Over and over again, I heard variations of “If I had known...” When asked for clarification, patients described being well informed about the technology of renal replacement. They understood the technical aspects of dialysis treatments. They knew treatment modality options and the mechanical aspects. What patients do not feel they, and their families, are fully prepared for is life with a chronic disease.

Even with Medicare paying 80% of direct hemodialysis costs, patients do not feel ready for the indirect financial costs of supplemental insurance, medications, and transportation. Patients feel even less prepared for the personal costs of decreased energy, frequent health crises, and loss of independence. Those patients who felt unprepared for the demands chronic illness would place on them, expressed even greater unpreparedness for the collateral demands that chronic illness would make on their families. Though patients faulted their physician for not preparing them for hemodialysis, the reality was that the information they lacked was psycho-social in nature. They understood the impact of disease, but not the impact of illness. Creating a conundrum for physicians, who must shift away from their own presumptions, is the contextual and constructed nature of illness versus the scientific nature of disease. The physician and patient must negotiate the meaning of illness, before they enter into a negotiation of disease management.

Further questions about what utility hemodialysis offers to patients brought forth narratives about responsibility. All women patients, who had children, spoke about responsibilities to family. Children and grandchildren were called, “The reasons why I do

this. If it weren't for them, I don't think it would be worth it." About half of the men spoke about owing responsibility to church or God as a reason to accept dialysis treatment. The sample was too small to generate a true understanding of how genders experience responsibility. However, the appearance of differing belief systems between women and men is intriguing enough to warrant further research.

What values are involved in the decision to pursue treatment when a cure is not possible?

Most findings were supported by the literature. Participant narratives described leading a meaningful life. Facets of living a life full of meaning were foreshadowed by the literature which spoke to finding personal and societal benefits. These social connections, connections to others, provided opportunities to both gain and offer support. The literacy on support reciprocity was borne out by participants and their membership in the illness community and their perceived contributions to it. Individuals had strong perceptions of their worth in their environments. These perceptions of providing support seemed to be integral to finding meaning in the losses manifested by chronic disease.

Participants listed love of family as a strong value contributing to the decision to pursue hemodialysis. Patients also talked about what they described as religious values. Prescriptions against suicide and a more complicated abrogation of suffering were both strong themes within the narratives of religion. Meeting these religious responsibilities was linked to pleasing God. When the meaning was obscured to the patient, its true meaning was known to God. This alignment with the purposes of God, whether as part of a formal religion or as part of a declared spirituality, was given by most participants as holding a tremendous value.

The value of autonomy was referenced directly or indirectly by all participants in their reflexive narratives. They recognized that they had a choice in accepting dialysis as a treatment. This accepted their organ failure as chronic, rather than its previous acuity. This meant a renegotiation of their self image and their image of illness and disease. This renegotiation could be furthered within the physician-patient relationship as both typical and atypical psycho-social responses to chronic illness were discussed. The discussion with the patient could also be facilitated by the nephrology social worker rather than the physician, depending on time and skill sets required.

A powerful theme emerging from the research on patient quality of life is the importance of world views held by patients before renal failure. Many patients in this study fit renal failure and dialysis into their pre-existing world views. Some patients maintained a positive world view by fitting illness into a greater schema of religion and benevolence. For some there was a grandiosity expressed through a belief that God was taking a special interest in their outcome.

For others a negative world view prevailed and bad luck was expected and perceived as morally neutral. They accepted a randomness of events which insulated them from distress. Not connecting their own actions to health consequences seems to contribute to some patients' non-adherence to prescribed treatments. For example, patients were non-adherent to diet recommendations, medication recommendations, hemodialysis time recommendations, and fluid restrictions. Patient world views allowed a consonance to develop between illness and expectations which could support non-adherence to treatment. Currently many staff see non-adherence as undermining the importance of treatment. Understanding the link between world views and adherence can help staff

from all disciplines to address non-adherence in an entirely different manner. An inability to see personal efficacy in being adherent to treatment requirements can effectively block seeing the value of adherence. If borne out by further research, this world view-adherence link could be of great importance to dialysis providers in addressing non-adherence to treatment.

What is lost in life to make further treatment futile in the patient's estimation?

Participants, when asked this question, first talked about the fears of loss of function or self image. They would choose to stop hemodialysis treatments if they were victims of a profound stroke or loss of multiple limbs. Further questions elicited discussions of patient fears and the loss of social connections in deciding further treatment is futile. The literature speaks to the changing, expanding, and long term demands on social supports. The literature, as well, references the quality and availability of support as well as research findings detailing an increase in the burden and frustration in support providers as chronic illness progresses. Hobfall's theory of conserving resources bears out patient fears that social supports could be overwhelmed by the demands of chronic illness.

Patients perception of the fragile and at risk social support, vulnerable to being overwhelmed by the demands of chronic illness and its treatment, tied into fears about treatment becoming futile. Patients are exquisitely aware of the demands of chronic disease places on their support structures. Many friends fall victim to what the field terms 'compassion fatigue'. Families respond with fervor during the initial acute phase of illness. But, as time goes on the very chronicity of the disease depletes both internal and external resources. Patients recognize the fragile nature of their ability to survive. They describe a careful, thoughtful pacing of demands on support networks. Patients use

superlatives like 'exhausted' and 'tired out' to describe those providing necessary support. For patients the preservation of support means the preservation of life. Its loss as care givers burn out can mean relinquishing that life.

Many patients used support from the dialysis patient community to their protect families from exposure to intensely emotional information. When patients needed to process the deaths of other dialysis patients or to initiate a discussion about their own disease exacerbation, they often approached members of the dialysis illness community. This strategy enabled the patient to rehearse and, if they felt necessary, modify the content of disclosures to family about disease and treatment issues. For example, patients were observed discussing potential loss of limbs and the possibility of discontinuing dialysis treatment. This ability to control disclosures to intimates allowed patients control over what they perceived to be levels of stress intolerable to families and so protect a support resource critical to survival.

Another theme contributing to the decision to continue or discontinue hemodialysis treatments was that of controlling the intense stressors encountered during hemodialysis treatments. Patients described, and I observed, a progressive ability to use dissociation as a protective strategy to insulate them from the effects of extremely traumatic dialysis events such as patients, within sight and hearing of other patients, vomiting, crying out in pain, or losing responsiveness. Dissociation is a psychological strategy in which individuals separate or split parts of the personality to accommodate situations or actions perceived as having a high enough degree of trauma to block integration into the understanding of the self. Patients narrated attempts to integrate their witnessing of the suffering of others with self-actions they would predict taking based on how they had

acted in the past. Since patients on hemodialysis are effectively tethered in place by their dialysis machines, dissociation can allow them to protect themselves from intolerable trauma. This trauma could rise to a level making further treatment evaluatively futile.

The issue of quality of life is moving to the forefront of medical decision making. We can better understand the contributory factors to quality of life for each patient by better understanding the nuanced context in which decisions are made. Understanding how caregivers and patients experience the ambiguous concept of quality of life can make explicit latent prejudices affecting the clinician-patient relationship. This co-constructed relationship becomes the critical field in which life and death decisions are made and the success or failure of medicine is defined by the patient.

Recommendations for Practitioners

This study has examined how hemodialysis patients perceive their quality of life, which can suggest conceptual models to improve treatment of dialysis patients. Knowing and understanding hemodialysis patients' fears and challenges can enlighten both future hemodialysis patients and all disciplines providing them care. True patient autonomy can only come about when their goals and values are kept central to any decisions about whether or not to initiate dialysis, how to proceed during dialysis, and decisions about discontinuing hemodialysis treatments. The hemodialysis patients who participated in this study give practitioners a framework within which to develop a model to initiate a meaningful dialogue. This dialogue should contain not only technical information, but it should also strive to understand the patient's world view and how treatment will impact the patient's life as he or she defines it.

Counseling about all facets of renal disease treatment, including providing patients opportunity to explore emotional readiness for ongoing dialysis treatments, should be offered to all patients and families. This counseling can be focused on both traditional family and friends as sources of support and on the utilization of the illness community itself to provide support. When patients initiate dialysis, his or her world view can be used as a therapeutic window into how the patient might respond to treatment recommendations, in essence a way to predict adherence. More sophisticated understanding of how the patient sees the universe and his or her place within it can provide powerful insight for care providers, allowing them to better enter the experienced world of the patient. Entering the world of the patient can offer the provider better tools to decrease trauma, better utilize support structures, and assist the provider to communicate effectively and respectfully with patients.

Recommendations for Further Research

Non-adherence to renal replacement treatment can be life-threatening, research into the link between a patient's world view and treatment adherence can solidify a theory able to inform practice and potentially save lives. Interventions targeted to decreasing world-view-based dialysis treatment non-adherence can give providers a direct link to cognitive-behavioral therapies which can be in the tool box of every discipline. Specific research recommendations would be to involve a larger participant base, the number drawn from the literature. The research instrument would have questions targeted to eliciting information about patient world view and its possible impact on patients' adherence to recommendations by health care providers. A well designed quantitative or qualitative approach could be utilized effectively.

Further research is also recommended into trauma occurring hemodialysis, a repetitive, endless trauma which is substantially different from other forms of trauma such as cancer, sexual abuse, or war. Research looking specifically at the function and role of dissociation in facing chronic and life-threatening situations would be valuable. A better understanding of the commonalities and differences between trauma types and the dissociative response will enhance knowledge in the fields of both trauma and chronic illness. Research comparing the levels of trauma experienced by home-dialysis therapy patients and by traditional center-based hemodialysis patients could be pivotal in evaluating the different dialysis modalities and may revise the default choice of hemodialysis over home therapy.

Research is also recommended into the secondary trauma experienced by professional care givers. Questions could be asked about their existing world views. Do they act to help care givers to meet the demands of working in chronic illness treatment? Does the same psychological need exist, as exists for patients, for the care giver to either accommodate care giving into an existing world view, or alternately, adapt their world view? Does dissociation play a role for care givers? Do care givers characterize their own support systems as vulnerable? Is there a link between care giver trauma and burn out?

This study coupled with future research can assist in better understanding of decision making in chronic illness and how it is impacted by subjective patient quality of life. As medical miracles become common place in the United States, the quality of life, in addition to quantity of life, becomes an important outcome measure for every treatment choice.

References

- Addington, T., Wegescheide-Harris, J., (1995). Ethics and Communication with the Terminally Ill. *Health Communication*, 7(3), 267-281.
- Atkinson, P., Coffey, A., Delamont, S., Lofland, J., Lofland, L., (2008). Handbook of Ethnography, Sage Publication, New York, NY.
- Atkinson, R., (1998). *The Life Story Interview*, London, England, Thousand Oaks, CA, and New Delhi, India, Sage Publication.
- Back, A.L., Arnold, R.M., Tulsky, J.A., Baile, W.F., Fryer-Edwards, K.A., (2005). On Saying Goodbye: Acknowledging the end of the patient-physician relationship with patients who are near death. *Annals of Internal Medicine*, 142, 682-685.
- Back, A.L., Arnold, R.M., (2006). Discussing Prognosis: "How Much Do You Want To Know?" Talking to patients who do not want information or who are ambivalent. *Journal of Clinical Oncology*, 24, 4214-4217.
- Back, A.L., Arnold, R.M., Baile, W.F., Tulsky, J.A., Fryer-Edwards, K.A., (2005). Approaching Difficult Communication Tasks in Oncology. *C.A. Cancer J.C.*, 55, 164-167.
- Baergen, R., (2006). How Hopeful Is Too Hopeful? Responding to unreasonably optimistic patients. *Pediatric Nursing*, 32.
- Bailey, C.A., (2007). A Guide to Qualitative Field Research, Thousand Oaks, CA, Pine Forge Press.
- Beauchamp, T.L. (Ed.) (1996). *Intending Death*, Prentiss Hall.

- Beck, A.L., Arnold, R.M., Tulskey, J.A., Baile, W.F., Fryer-Edwards, K.A., (2005). On Saying Goodbye. Acknowledging the end of the patient-physician relationship with patients who are near death. *Annals of Internal Medicine*, 142(8), 682-686.
- Blendon, R.J., DesRoches, C.M., Brodie, M., et al., (2002). Views of Practicing Physicians and the Public on Medical Errors, *New England Journal of Medicine*, 347, 1933-1940.
- Bosk, C.L., (2003). *Forgive and Remember: Managing Medical Failure*, Chicago, IL and London, England, University of Chicago Press.
- Brennan, T.A., (1999). Hospital Peer Review and Clinical Privileges Actions: To Report or Not Report, *Journal of the American Medical Association*, 282, 381-382.
- Cantor, M.D., Braddock, C.H., Derse, A.R., Edwards D.M., et al., (2003). Do Not Resuscitate Orders And Medical Futility. *Archives of Internal Medicine*, 163, 2689-2684.
- Cozby, P.C., (2006). *Methods in Behavioral Research*, McGraw Hill
- Creswell, J.W., (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Thousand Oaks, CA, London, England, New Delhi, India; Sage Publications.
- Creswell, J.W., (1997), *Qualitative Inquiry and Research Design*. Thousand Oaks, CA & London, England; Sage Publications.
- Dash, N., (1993). *Selection of the Research Paradigm and Methodology*, Online Research Methods.
- Denzin, N., (1989). *Interpretive Biography*. London, England, Thousand Oaks, CA, and New Delhi, India; Sage Publications.

- Epstein, Richard A., (1999). *Mortal Peril Our Inalienable Right to Health Care*. Perseus Books; Cambridge, MA.
- Feldman, M.S., (1995). *Strategies for Interpreting Qualitative Data*. Thousand Oaks, CA; Sage Publications.
- Fine, R.L., Mayo, T.W., (2003). Resolution of Futility by Due Process: Early experience with the Texas Advance Directives Act, *Annals of Internal Medicine*, 138, 743-746.
- Frank, A.W., (2002). How Can They Act Like That? Clinicians and patients as characters in each other's stories. *The Hastings Center Report*, 32.5:14(10).
- Fulford, K.W.M., Dickenson, D.L., Murray, T.M., (2002). *Healthcare Ethics and Human Values*. Blackwell Publishing; MA.
- Gabe, J., Bury, M., Elston, M., (2004). *Key Concepts in Medical Sociology*. London, England; Sage Publications.
- Gaskins, S. & Brown, K., (1997). Helping Others: A Response to HIV Disease, *Journal of the Association of Nurses in Aids Care*, Vol. 8, No. 3.
- Gephart, R., (1999). *Paradigms and Research Methods*. University of Alberta, Canada.
- Goldberg, P.E., (2000). The Physician-Patient Relationship. *Archives of Family Medicine*, 9, 1164-1168.
- Goodheart, C.D., Lansing, M.H., (1997). *Treating People with Chronic Disease: A Psychological Guide*, American Psychological Association.
- Goold, S.D., Williams, B., Arnold, R.M., (2000). Conflicts Regarding Decision to Limit Treatment, *Journal of the American Medical Association*, 283, 909-914.

- Gutch, C.F., Stoner, M.H., Corea, A.L., (1983). Review of Hemodialysis for Nurses and Dialysis Personnel, 5th Edition. Mosby Book; St. Louis, MO
- Hallenbeck, J., (1999). Decisions at the End of Life: Cultural considerations beyond medical ethics, *Generations*, 23, 24.
- Helft, P.R., Siegler, M., Lantos, J., (2000). The Rise and Fall of the Futility Movement, *New England Journal of Medicine*, 343, 293-296.
- Hertlein, K., Lambert-Shute, J., Benson, K., (2004). Postmodern Influence in Family Therapy Research, *Qualitative Report*, Vol. 9, No. 3.
- Holstein, J. & Gubrium, J., (1995). London, England, Thousand Oaks, CA, and New Delhi, India, Sage Publication.
- Hurwitz, B., Greenhalgh, T., Skultans, V., (2004). Narrative Research in Health and Illness. British Medical Association.
- Jenkinson, C., (2002). Assessment and Evaluation of Health and Medical Care. Open University Press; PA.
- Journal of American Medical Association*, (1999). Medical Futility in End of Life Care. Report of the Council on Ethical and Judicial Affairs, 281, 937-941.
- Kelly, D.F., (2004). Contemporary Health Care Ethics, Georgetown Press, Washington, D.C.
- Kitchens, L.W., Brennan, T.A., Carroll, R.J., et al., (1998). Ethics Manual: Fourth Edition. *Annals of Internal Medicine*, 128(7), 576-594.
- Krauss, S., (2005). Research Paradigms and Meaning Making, *Qualitative Report*, Vol. 10.

- LeCompte, M.D., Schensul, J.J., (1999). *Designing and Conducting Ethnographic Research*. Altamira Press; M.D.
- LeCompte, M.D., Schensul, J.J., Weeks, M.R., Singer, M., (1999). *Researcher Roles and Partnerships*. Altamira Press; CA.
- LeCompte, M.D., Schensul, J.J., (1999). *Analyzing and Interpreting Ethnographic Data*. Altamira Press; CA.
- Lo, B., Quill, T., Tulsky, J., (1999). *Discussing Palliative Care with Patients*. *Annals of Internal Medicine*, 130, 744-749.
- Loewy, Erich H., Loewy, Roberta Springer, (2000). *The Ethics of Terminal Care Orchestrating the End of Life*. Plenum Publication; New York, Boston, London, England, Moscow.
- Mackenzie, N., Knipe, S., (2006). *Research Dilemmas: Paradigm Methods and Methodology*, *Issues in Educational Research*, Vol. 16.
- Martz, E., Livneh, H., (2007). *Coping with Chronic Illness and Disability*; Springer Publications.
- McDaniel, S.H., Hepworth, J., Doherty, W.J., (1992). *Medical Family Therapy: A Biopsychosocial Approach to Families with Health Problems*. Perseus Book Group.
- McDowell, I., (2006). *Measuring Health: A Guide to Rating Scales and Questionnaires*. Oxford University Press.
- McGee, D.C., Weinacker, A.B., Raffin, T.A., (2000). *The Patient's Response to Medical Futility*. *Archives of Internal Medicine*, 160, 1565-1566.
- Mishler, E.G., (1986). *Research Interviewing*. Harvard University Press; MA.

- Montgomery, K., (2006). *How Doctors Think*. Oxford University Press.
- Murchison, J.M., (2010). *Ethnography Essentials. Designing, Conducting, and Presenting Your Research*; Jossey-Bass, CA.
- Neibroj, L.T., (2006). The Influence of Religious Beliefs on Health Care: Between Medical Futility and Refusal of Treatment. *Journal of Physiology and Pharmacology*, 57, 241-249.
- Neimeyer, R.A., (2001). *Meaning Reconstruction and the Experience of Loss*; American Psychological Association.
- Nettleton, S., (2006). *The Sociology of Health and Illness*; Cambridge Polity Press.
- O'Brien, J., (2006). *The Production of Reality*, Pine Forge Press; CA.
- Patton, M., (2002). *Qualitative Research and Evaluation Methods*; Sage Publication.
- Peterson, C. & Martin,C., (1992). *A New Paradigm in General Practice Research: The Utilization of Multiple Research Methodologies in General Practice*; Australia.
- Pope, C. & Mays, N. (Eds.), *Qualitative Research in Health Care*. Mass., Oxford; Blackwell Publishing, Ltd.
- Power, P.W., Dell Orto, A.E., (2004). *Families Living with Chronic Illness and Disability: Interventions, Challenges and Opportunities*, Springer Publication; New York, NY
- Quill, T.E., (2000). Initiating end-of-life discussions with seriously ill patients. *Journal of the American Medical Association*, 284(19, 2505-2407.
- Quill, T.E. & Brody, H., (1996). Physician Recommendations and Patient Autonomy: Finding a balance between physician power and patient choice. *Annals of Internal Medicine*, 125(9), 763-769.

- Quill, T.E. & Cassel, C.K., (1995). Nonabandonment. A central obligation for physicians. *Annals of Internal Medicine*, 122(5), 368-374.
- Riessman, C.K., (1993). Newbury Park, California and London, England and New Delhi, India; Sage Publication.
- Riessman, C.K., (1993). Narrative Analysis; Sage Press.
- Rolland, J.S., (1994). Families, Illness, and Disability; Basic Books.
- Ross, A.S., (2001). Caring and Doing for Others: Social Responsibility in the Domains of Family, Work, and Community, University of Chicago Press; Chicago, IL.
- Rubin, Susan B., (1998). When Doctors Say No the Battleground of Medical Futility. Indiana University Press; Bloomington and Indianapolis, IN.
- Saint Patrick Hospital and Health Care Sciences, Decisions about using or foregoing life-prolonging treatment policy, effective 5-94.
- Schensul, S.L., Schensul, J., LeCompte, M.D., (1999). Essential Ethnographic Methods: Observations, Interviews, and Questionnaires, Altamira Press; New York, NY.
- Schensul, J.J., LeCompte, M.D., Trotter, R.T., Cromley, E.K., Singer, M., (1999). Mapping Social Networks, Spatial Data, and Hidden Populations, Altamira Press; CA.
- Schensul, J.J., LeCompte, M.D., Nastaski, B.K., Borgatti, S.P., (1999). Enhanced Ethnographic Methods; Altamira Press, MD.
- Schostak, J., (2006). Interviewing and Representation in Qualitative Research, Berkshire, England; Open University Press.
- Seidman, I., (2006). Interviewing as Qualitative Research, New York, NY; Teachers College Press.

- Snyder, L. & Leffler, C., (2005). Ethics Manual, 5th Edition. *Annals of Internal Medicine*, 142, 560-582.
- Steinbock, B., Arras, J.D., London, A.J., (2003). Ethical Issues in Modern Medicine, McGraw Hill, NY.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., et al., (2000). In search of a good death: Observations of Patients, Families, and Providers. *Annals of Internal Medicine*, 132, 825-832.
- Tonelli, M.R., (2005). Waking the dying; Must we always attempt to involve critically ill patients in end-of-life decisions. *American College of Chest Physicians*, 127, 637-642.
- Uhlmann, M.M., (Ed.) (1998). Last Rights? Eerdmans Publishing Company; Grand Rapids, MI.
- Waisel, D.B., Truog, R.D., (1995). The cardiopulmonary resuscitation not indicated order. Futility revisited. *Annals of Internal Medicine*, 122, 304-308.
- Walker, K.L., Arnol, C.L., Miller-Day, M. & Webb, L.M., (2001). Investigating the Physician-Patient Relationship: Examining emerging themes. *Health Communication*, 14(1), 45-68.
- Way, J., Black, A.L., Curtis, J.R. (2002). Withdrawing life support and resolution of conflict with families. *BMJ*, 325, 1342-1345.
- Williams, E., (1998). Research and Paradigms, London, England, Victoria University.
- Williamson, K., (2006). Research in Constructivist Frameworks using Ethnographic Techniques, *Library Trends*, Vol. 55, No. 1.

Wolpin, B.M., Chaabner, B.A., Lynch, T.J., Penson, R.T., (2005). Learning to Cope:

How far is too close? *The Oncologist*, 10, 449-456.

Zucker, Marjorie B., Zucker, Howard D., Ed. (1997). Medical Futility and the

Evaluation of Life-Sustaining Interventions, Cambridge University Press;

Cambridge, MA.