

AN ABSTRACT OF THE THESIS OF

Kelly Marie van Bronkhorst for the degree of Master of Arts in Applied Anthropology
presented on December 1, 2011.

Title: Improving Health Information: An Anthropological Perspective of Health
Literacy among Chronic Disease Patients

Abstract approved:

Sunil Khanna

This research examines the relationship between health literacy among End Stage Renal Disease (ESRD) patients and its relevance for communication between patients and providers. The study was conducted among dialysis services providers at the Good Samaritan Dialysis Center and dialysis patients receiving care at the Center. Data collection techniques included individual interviews, surveys, and the Short Test of Functional Health Literacy in Adults (S-TOFHLA), which measured the health literacy level of the participants. The results of the study show that a large majority of the patients have “adequate” health literacy, which contradicts the provider’s perceptions of the patient’s ability to comprehend health information. Provider’s perspectives are shaped by their training and work environment. The study suggests that structural barriers and communication issues impede effective patient-provider interactions. This issue is especially serious for those chronic disease patients who have limited self-management skills.

© Copyright by Kelly Marie van Bronkhorst

December 1, 2011

All Rights Reserved

Improving Health Information: An Anthropological Perspective of Health Literacy
among Chronic Disease Patients

by
Kelly Marie van Bronkhorst

A THESIS

submitted to

Oregon State University

in partial fulfillment of
the requirements for the
degree of

Master of Arts

Presented December 1, 2011
Commencement June 2012

Master of Arts thesis of Kelly Marie van Bronkhorst presented on December 1, 2011.

APPROVED:

Major Professor, representing Applied Anthropology

Chair of the Department of Anthropology

Dean of the Graduate School

I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

Kelly Marie van Bronkhorst, Author

ACKNOWLEDGMENTS

The sole substitute for an experience which we have not ourselves lived through is art and literature.

-Aleksandr Solzhenitsyn

First and foremost I would like to thank the patients and providers for allowing me to enter their lives and for sharing their personal experiences and perceptions which have revealed a clearer picture of the barriers that they face. I want to thank the providers for their kindness and involvement in making my research a reality.

This project would not have been able to take off without the collaboration of research director Dr. Jana Slater and IRB administrator Lisa Leventhal. I can't thank them enough. Thank you Dr. Ribback and Mr. Roberts for your grammatical corrections and advice.

I want to thank my friends and family for giving me the love and support to make it through my writing process. Last but not least I would like to thank Dr. Sunil Khanna for bringing me to the attention of ESRD and health literacy.

TABLE OF CONTENTS

	<u>Page</u>
CHAPTER 1: Bio-Medicine and Anthropology	1
1.1 Introduction.....	2
1.2 The Study	3
1.3 Bio-Medical Backgrounds.....	5
1.3.1 Causes of ESRD.....	6
1.3.1.1 Diabetes and ESRD.....	6
1.3.1.2 Cardiovascular Disease	7
1.3.1.3 Hypertension	8
1.3.2 Symptoms of ESRD	9
1.4 Treatment Options.....	11
1.4.1 Hemodialysis.....	13
1.4.1.1 Fistulas and Risks.....	15
1.4.2 Peritoneal Dialysis	16
1.4.2.1 Catheters and Risks.....	17
1.5 Nutrition.....	18
1.5.1 Nutrition requirements	18
1.6 Research and Design.....	22
1.6.1 History of Health Literacy	23
1.6.2 Chronic Disease and Health Literacy.....	24
CHAPTER 2: The Political-Economy of Health Care.....	27
2.1 The Neo-Liberal Dillema.....	27
2.1.1 Neo-Liberalism and ESRD	27
2.1.1.1 Cost Containment in Dialysis.....	29
2.1.2 The Modern Patient.....	31
2.1.3 Doctor-Patient Relationships	34
2.1.3.1 Explanatory Model.....	37
2.1.3.2 Explanatory Models of Physicians.....	38
2.1.3.3 Critical Medical Anthropology	40

TABLE OF CONTENTS (Continued)

	<u>Page</u>
CHAPTER 3: METHODS AND ANALYSIS.....	43
3.1 Research and Design.....	44
3.1.1 Patient and Provider Participation.....	44
3.1.1.1 Informed Consent	45
3.1.2 Interviews and Survey.....	46
3.1.3 S-TOFHLA	48
3.1.4 Samaritan Dialysis Services.....	49
CHAPTER 4: RESULTS AND DISCUSSION.....	53
4.1 Patient and Provider Demographics.....	53
4.1.1 Health Literacy Results.....	57
4.1.2 Provider Demographics.....	63
4.2 ESRD Patient Care: Provider Perspective.....	66
4.2.1 Renal/Diabetic Diet.....	66
4.3 The Correlation Between Health Literacy and Education.....	71
4.3.1 The Difficult Patient.....	73
4.4 The Difficult Patient.....	74
4.4.1 Autonomy and Self Interest.....	78
4.4.2 Control and Denial	80
4.5 Medical Gaze and the Ideal Patient.....	83
4.6 Health Literacy Results.....	86
4.6.1 Nurses.....	88
4.6.2 Technology.....	91
4.6.2.1 Teamwork and Communication.....	98
4.7 Challenges: Space and Efficiency.....	100
CHAPTER 5: CONCLUSION.....	101
References	111
Appendix A: Surveys of Patients and Providers.....	119
Appendix B: S-TOFHLA.....	122

LIST OF FIGURES

<u>Figure</u>	<u>Page</u>
Figure 1. Compounding Events Leading to ESRD	9
Figure 2. Treatment Modalities for ESRD Patients	12
Figure 3. Phases of Data Collection for Patients.....	44
Figure 4. Phases of Data Collection for Providers.....	44
Figure 5. Total Poulation for Corvallis, Oregon	49
Figure 6. Ethnicities in Corvallis; 2000 Census.....	51
Figure 7. Urban versus Rural Dialysis Population	54
Figure 8. Distribution of Patient Population throughout the Mid-Valley	56
Figure 9. Patient Income	55
Figure 10. Patient Health Insurance	55
Figure 11. Health Literacy versus Education.....	57
Figure 12. Health Literacy versus Age	59
Figure 13. Marital Status.....	61
Figure 14. Health Literacy Levels of Participants	62
Figure 15. Provider Ethnicity	63
Figure 16. Provider Income.....	64
Figure 17. Occupation versus Age.....	64
Figure 18. Job Satisfaction.....	65
Figure 19. Occupation versus Satisfaction.....	65
Figure 20. Relationship Between Patient Care and Provider Perspectives.....	66

LIST OF FIGURES (Continued)

<u>Figure</u>	<u>Page</u>
Figure 21. Income versus Age	70
Figure 22. Provider Themes Regarding Non-Compliance and Compliance.....	71
Figure 23. Information in Relation to Knowledge Utilization and Teamwork.....	75
Figure 24. Health Information Provided	76
Figure 25. Job Title versus Education.....	93

LIST OF TABLES

<u>Table</u>	<u>Page</u>
Table 1. Prevalence Rates and Kidney Stages	6
Table 2. Advantages and Disadvantages of Hemodialysis	17
Table 3. Appropriate Foods for the Renal/Diabetic Diet	19
Table 4. Health Literacy Levels in Relation to Demographic Characteristics.....	60
Table 4. Providers List of Duties to Prioritize	67

Improving Health Communication: An Anthropological Perspective of Health Literacy among End Stage Renal Disease Patients

CHAPTER 1: Bio-medicine and Anthropology

1.1 Introduction

The patient-provider relationship has taken a common stance within literature throughout the decades. Widespread patient dissatisfaction with care and non-adherence to treatment exemplify the issues that have been studied extensively by a variety of social scientists (Lazarus 1988: 34). Dissatisfaction and non-adherence could be partially explained by bio-medicine, which some scientists view as a socio-cultural system which has created an unbalanced relationship of obedience and instruction between the patient and the provider (Neuberger 2000: 247). Issues of power and control in the patient-provider relationship were central to the socio-political critiques of medicine, particularly the feminist critiques of medical patriarchy that reached their zenith in the 1970s (Mead et al. 2000: 1089).

Physicians were seen as partially responsible for patients' non-compliance and dissatisfaction with their treatment. In light of this, medical schools began to advocate a 'patient-centeredness' approach, which was an attempt to understand patients' illnesses and their needs from their doctor. This psychosocially oriented discourse is often regarded as a radical departure for medicine but is actually quite conservative (Salmon et al. 2003: 1972). For example, what physicians call 'listening to the patient' and 'taking the history' are medicalized tasks directed not at understanding the patient's life but as diagnostic evidence (Hahn et al.).

In order to respond to issues and problems of patient health care, especially in terms of satisfaction with treatment and adherence, two key analytical approaches have emerged. The first approach is Arthur Kleinman's explanatory model (EM), which focuses on what sickness and health mean to individuals and how it affects their lives (Lazarus 34). This is crucial to understanding the provider's perspective of health literacy because in the clinical encounter both doctor and patient bring unconscious and conscious beliefs and expectations that do not easily fit into the model of rationality assumed by the evidence-based medicine approach (Kleinman et al. 1983: 307).

The second approach is critical medical anthropology (CRM), which is a theoretical and practical approach in the consideration of health, illness, and treatment in terms of the political-economy (Singer 1995: 81). This approach has in part risen out of dissatisfaction with the failure of anthropological studies to examine individual beliefs and actions in light of the larger political-economy (Lazarus 34).

Both approaches will help reveal the present medical situation in terms of health literacy, defined as the ability to understand and act upon basic health information. This is one of the most pressing issues facing national health care in the United States, especially serious for chronic disease patients because they are more directly involved in their health care and need to manage their own illness. Studies in an indigent population indicate that patients with low health literacy skills and chronic diseases such as diabetes, asthma, or hypertension have less knowledge of their disease and its treatment, as well as fewer correct self management skills than literate patients (Gazamarian et al. 2003).

One such chronic disease that is gaining increased attention is End Stage Renal Disease. This disease is a culmination of cardiovascular disease and type II diabetes. The latter, in regard to health literacy, has been studied over several decades; however, research concerning the relationship between health literacy and end stage renal disease is extremely limited.

1.2 The Study

This study seeks to understand the relationship between health literacy (HL) among End Stage Renal Disease (ESRD) patients and its relevance for communication between patients and providers. There are key gaps in the literature concerning HL assessment and perception among ESRD patients. The research that is missing is a prerequisite for improving clinical outcomes.

The first aim of the study is to understand the provider's perspective of health literacy among End Stage Renal Disease patients (ESRD). I interviewed key health care providers (nurses, physicians, and office staff) to understand their perceptions of patients' health literacy levels because they have the most direct and regular access to ESRD patients. The second aim is to find out what the level of health literacy is among ESRD patients. The S-TOFHLA test (Appendix A) ranks the patients HL levels according to their correct responses in a seven minute time frame.

The final aim of this study is to find the level of concurrence between the two (perceived and assessed) levels of health literacy. The providers' perspective, paired with the health literacy test findings, will act as a tool to recognize any relationship that emerges between the patient's actual health literacy skills and the provider's perception thereof.

This study not only will contribute to designing and implementing effective strategies for communication between providers and chronic disease patients but will also improve clinical and health outcomes among patients, as well as reducing medical costs. At a theoretical level, the project contributes to the discipline of medical anthropology by drawing from the explanatory model (EM) to unlock the provider's perspective.

Previous studies have utilized the EM to understand the patient's experiences of health and illness. However, by solely concentrating on eliciting and interpreting patients' EMs, the study is forced away from a critical evaluation of the provider's own role in the interaction. The EM of the provider allows for their perspectives to be

framed within the biomedical system in which they function, where set rules and regulations govern their activities. This in turn allows for a critical medical anthropological approach to analyze the provider within the dialysis center. This could potentially contribute towards a system challenging praxis which will strive to heighten social action towards an improved understanding of the provider's perspective of health literacy.

Further, this project contributes to a current body of literature which demonstrates a macro approach to provider's perceptions, resulting in the term *modern patient* (Buetow et al. 2009; Dieterich 2007; Tomes 2007), which generalizes the experiences and perceptions of providers. The emic approach exhibited by this study will promote a larger understanding of potential structural barriers that providers themselves could be facing within the medical system which hinders their ability to affectively promote health literacy.

Finally, the project contributes to gender studies. The perspectives of the providers and how they use their agency will illuminate their voices within a historically male dominated establishment. Nurses are the care takers of the health industry, and they are in a hierarchical position, intermediary between the physician and the patient.

The first chapter is dedicated to understanding the complex relationship between chronic disease and health literacy. A thorough examination of the biomedical background of ESRD will reveal the challenges that patients face when adhering to a series of treatment modalities and dietary restrictions while having to cope with the consequences of having two or more chronic diseases. The second chapter places dialysis and ESRD within a neo-liberal framework which will reveal cost-containment issues and structural barriers that providers face. The third chapter is the methods and analysis chapter. The fourth and fifth chapter reveal the results and conclusions of the study.

1.3 Biomedical Background

Humans are born with two kidneys, and they are each the size of a fist, located behind the backbone. The importance of the kidneys and how the kidney functions is beyond the scope of the discussion; however, the simplified explanation is that they filter waste, toxins, and extra fluids from blood. If the kidneys are no longer able to do this, individuals will die from septicemia, which is the presence of bacteria in the blood. The national U.S. Renal Data System (USRDS) registry indicates that infection is the second leading cause of death in patients with ESRD following cardiovascular disease, and septicemia accounts for more than 75% of these infectious deaths (Sarnak 2000).

The American public has been shifting from acute, episodic therapy to long-term treatment of chronic conditions (Kopyt 2006: 133). Chronic conditions such as type II diabetes and cardiovascular disease (CVD) are detrimental to the kidneys ability to function. There are five stages of chronic kidney disease (CKD) as determined by the National Kidney Foundation (**See Table 1**). Stage 5 is irreversible, and transplant or dialysis is the only treatment option. The following diagram describes the stage, and how it is related to the glomerular filtration rate (GFR). The GFR is the measurement of the kidneys' ability to filter fluid and is an important tool in diagnosing kidney disease. According to this chart, 10.9% of the United States population has kidney disease.

The National Kidney Foundation estimated that approximately 8 million individuals have a GFR of <60 ml/min, and that 5.9 million of these individuals appear to be in the Medicare system within the group of enrollees aged 65 years and older (Collins et al. 2003). ESRD affects ethnicities disproportionately. According to a recent study, people from indigenous or migrant ethnic minority populations have increased susceptibility to CKD, due to structural barriers such as socio-economic status and location. There is a three to four fold increase in the incidence of ESRD in South Asian and African Caribbean populations in the UK, and there are similar

increases in African Americans, Hispanics, and Native Americans in the US (Feehally 2010: 126).

Table 1. Prevalence Rates and Kidney Stages

Stage	Description	GFR (ml/min.1.73m ²)	U.S. Prevalence (%)
1	Kidney damage with normal or increased GFR	>90	3.3
2	Kidney damage with mildly decreased GFR	60-89	3.0
3	Moderately decreased GFR	30-59	4.3
4	Severely decreased GFR	15-29	0.2
5	Kidney Failure	<15 or dialysis	0.1
			10.9%

1.3.1 Causes of ESRD

ESRD is primarily caused by chronic conditions such as type II diabetes, cardiovascular disease (CVD) and hypertension. Other cardiovascular diseases that occur in patients with ESRD include coronary atherosclerosis, heart failure, ischemic heart disease, and aortic and arterial stiffening (Kopyt 2005).

However, traumatic accidents, infections, immune disorders, lupus, and over-the-counter medicines can cause kidney failure as well. Kidney disease can be acquired through heredity, which is called Polycystic Kidney Disease (PKD). There are approximately 600,000 individuals that have PKD (Kidney Foundation)

1.3.1.1 Diabetes and ESRD

Patients with type II diabetes now account for 45% of the prevalent ESRD population in the US. The rate of ESRD caused by diabetes increased 86% between 1993 and 2003 (Williams 2006). Diabetics with a diagnosis of CKD have a mortality rate of almost 32% within the first two years of their diagnosis (Collins et al. 2003). The number of adults with diabetes worldwide will grow from 135 million (1995) to 300 million (2025) (Gerth et al. 2002). The staggering numbers of the growing population are posing problems for physicians to provide dialysis services in an

industry that costs \$6 billion a year to maintain, which is approximately 3% of the Medicare budget (Mohanram et al. 2004).

Glycemic control is fundamental to the management of diabetes and its complications, and relies on monitoring of hyperglycemia (Williams et al. 2006). Without proper management, cardiovascular disease becomes increasingly probable. Among patients with diabetes in a large prospective study, high blood glucose concentrations were associated with a greater incidence of cardiovascular disease (Williams et al. 1503). Powel *et al* recently demonstrated that older age and the presence of type II diabetes were the strongest predictors of risk for developing septicemia in HD or PD patients (Sarnak 2000). The body's ability to ward off infection is compromised.

The risk of developing ESRD is much higher with Type II than Type I. Virtually no studies have examined the link between Type I diabetes and ESRD. Of the studies available, Reunanen et al. looked at long-term data on more than 20,000 patients with Type I diabetes and found the risk of developing ESRD within 30 years after diagnosis was approximately 7.8% lower than previously reported rates of up to 17% (Reunanen et al. 2005). This was based on a study in Finland, which has the highest rates of Type I diabetes in Europe. The risk of developing ESRD is equally distributed among Type I and Type II diabetic patients. In the United States, the prevalence rate of Type II diabetics is higher than that of patients with Type I diabetes, therefore Type II is a primary concern for this research.

1.3.1.2 Cardiovascular Disease

According to The National Kidney Foundation, Cardiovascular Disease (CVD) is the third leading cause of CKD and ESRD (Kidney Foundation). The prevalence of CVD at initiation of dialysis increased dramatically from 25% in 1984 to 40% in 1994 (Marrs et al. 2010, Collins 2003). This increase is problematic in that patient's without a diagnosis of CKD (with or without diabetes) are approximately 49 to 128 times more

likely to die than to reach ESRD (Colins et al., Foley et al. Kopyt 2006). It could be speculated that the prevalence of CVD within CKD patients are far higher than the research shows.

Dyslipidemia is a well established independent risk factor for CVD in the general population, with low-density lipoprotein cholesterol (LDL) as the primarily lipid treatment target (Marrs et al. 2010). A randomized controlled trial demonstrated that mild renal insufficiency is a major risk factor for adverse cardiovascular events (Kopyt 2006). If the severity of CVD can be targeted before dialysis begins, the mortality rates of the patients could decrease.

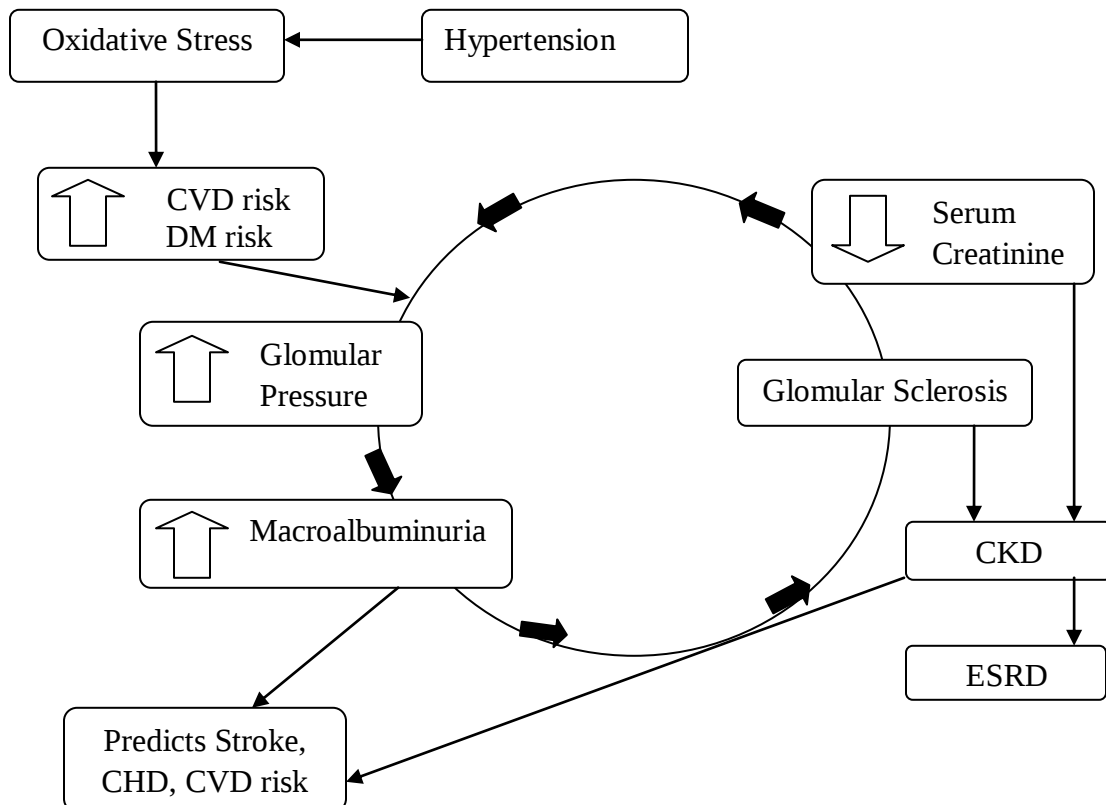
Epidemiological data support the role of cholesterol lowering as a means to reduce cardiovascular events in the hemodialysis population (Marrs et al. 2010). Lipid abnormalities associated with renal disease were originally thought to be isolated to patients with ESRD; however, over the past decade, lipid changes have been documented in patients with stages 2-4 in CKD (Marrs et al. 824).

1.3.1.3 Hypertension

Hypertension causes oxidative stress, which occurs when there is an imbalance between the production and manifestation of reactive oxygen species. Free radicals are an example of reactive oxygen species, which damage tissue over time. The blood vessels constrict, reducing the kidneys ability to detoxify and repair resulting damage. Hypertension leads to an increased risk of cardiovascular disease (CVD) and type II diabetes. The glomular pressure increases, indicating a reduced function of the kidneys. The glomeruli are nephrons in both kidneys which filter waste. When the glomeruli are damaged, proteins such as abumin leak into the urine, causing a rise in microalbuminuria. Microalbuminiuria is now recognized as an important marker of renal disease and CVD (Kopyt 208). Where other markers such as creatinine concentration and clearance are within normal limits, microalbuminuria is present. Microalumbinuria is measured through laboratory assessments of 24-hour urine

collection, timed collection, or spot collection (Kopyt 2005). The following diagram (**Figure 1**) gives a simplified overview of the process.

Figure 1. Compounding Events leading to ESRD.



1.3.2 Symptoms of ESRD

It isn't until the kidneys are failing that the symptoms start to become apparent. The following are two common side effects of failing kidneys that require additional treatment and knowledge about diet. Symptoms such as itching, red eyes, increased appetite, high blood pressure, yellowing tint to the skin, and loss of ability to urinate are some of the symptoms that individuals face.

Damaged kidneys no longer have the ability to produce enough vitamin D.

Vitamin D is required to increase the circulation of calcium and phosphorous, two minerals necessary for healthy bones. The decrease in vitamin D production leads to the over production of PTH, which is a hormone that is released by the parathyroid gland. This hormone helps maintain calcium and phosphorus levels. Vitamin D is needed to help the parathyroid gland release the right amount of PTH. If the vitamin D is not supplied, complication such as bone fractures will occur. Vitamin D is administered intravenously during dialysis. Although it is known that vitamin D can be found in vegetables such as broccoli and milk, these can no longer be consumed because phosphorous levels will rise, resulting in other problems. This will be discussed further in a later section.

Although it is known that sun exposure provides Vitamin D, ESRD patients must avoid UV rays. Because of chronic dehydration, the patient's skin is usually dry and has a poor texture. Some patients experience firm plaques or nodules on the surfaces of the larger joints with a chalky material exuding because of calcium deposits in the skin (Taylor 2001). Management of the skin is difficult, and patients need to be educated about sun protection and establish a skin examination procedure to prevent infections and skin malignancies.

Depending on the stage of progressive renal failure of the patient, it is difficult for primary care physicians to detect failure because the symptoms could mirror other problems resulting from comorbidities. The use of the glomerular filtration rate (GFR) is a reliable indicator of renal function. Currently (2010), it indicates an estimated 8.3 million people in the United States have chronic kidney disease (CKD); of these, 5.9 million have stage 1 renal disease, and 300,000 are in stage 5, which is kidney failure (Kopyt 2007).

The detection of kidney disease, however, has spurred a flurry of new dialysis patients, patients whose GFR are above 15%, the marker for ESRD. In both 1996 and 2005, there was a gradual increasing trend towards initiating dialysis for patients who had higher levels of GFR with age (Rosansky 2009). One study found that the percentage of patients starting dialysis with GFR greater than 10ml/min per 1.73m²

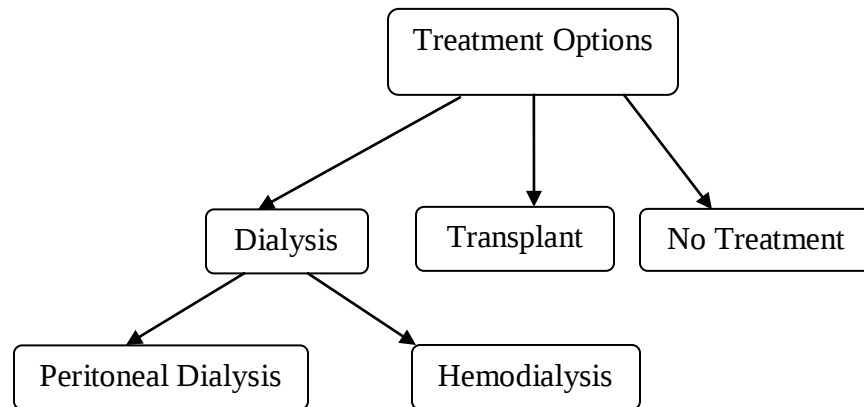
more than doubled between 1996 and 2005, from 25 to 54%, whereas in France it has been stable at 30% (Lasalle 2010). An analysis done by Rosansky et al. found a higher mortality risk with higher GFR start times. Patients ages 65-74 years with a GFR of 5-9.9ml/min per 1.73 m² have a 25% first year mortality rate, and similarly aged patients with a GFR >15 have a 41.5% first year mortality rate (Rosansky 2009). Another study done by Lasalle et al. also found evidence that each 5ml increase in GFR was associated with a 40% increase in crude mortality risk (Lassalle et al. 2010). Other studies are following suit, for there is inconclusive evidence of a clear benefit to starting dialysis early.

Medicare is currently straining under the burden of patients on dialysis. The addition of individuals with GRFs >20 are creating additional, unnecessary costs. Preventative measures to ensure that patients do not reach ESRD are necessary to keep costs down. However, depending on causality, the nephrologist must rely on several other factors to ensure that the patient receives dialysis in a timely manner.

1.4 Treatment Options

There is no cure for ESRD. The only available treatments options are designed to maintain the current residual renal function (RRF). Maintaining any function of the kidney is important for several reasons. First, dialysis treatment becomes more efficient. Second, solute clearances ensured by the native kidney are more significant than clearances delivered by renal replacement therapies, either hemodialysis (HD) or peritoneal dialysis (PD) (Canaud et al. 2006). RRF also is essential in reducing the need for dietary and salt fluid restrictions. **Figure 2** shows the following treatment modalities.

Figure 2. Treatment Modalities for ESRD Patients



Therefore, treatment options depend not only on the stage of kidney disease, but also the individual's RRF. Patient related factors such as age, causal nephropathy, and comorbid conditions such as chronic kidney disease (CKD), hypertension, and diabetes play a role the individuals RRF. It has been shown that PD helps maintain an individual's RRF for a longer period of time than HD (Canaud et al. 2006; Rosanksy et al. 2009).

Depending on the aforementioned factors, hemodialysis and peritoneal dialysis are the current treatment modalities available. The individual can opt for no treatment, which will result in an eventual death. However, a transplant is the only viable option to end dialysis and is associated with significantly extending the life of the individual up to ten to fifteen years (Luan et al. 200). The ultimate benefit of receiving a kidney is the ability to function without the aid of dialysis and to lead a life with fewer restrictions.

There are two ways to obtain a kidney: from a willing donor such as a friend, family member, or from a cadaver. However, with growth in the incidence and prevalence of kidney disease and a shortage of donor organs, more patients are remaining on dialysis for a longer term (Stanley 24). A dwindling supply of kidneys are not the only problem facing ESRD patients. There are a plethora of barriers that patients face in order to be placed on the transplant list, including age, weight, blood

type, cross matching, and medical criteria including comorbidities such as CVD. The wait list is usually a period from two to three years, in which the patient must be on call at all times. More than 86,000 patients with ESRD are currently waiting for a kidney transplant and a little more than 13,000 kidney transplants are performed annually in the United States (Luan et al. 199).

Once a transplant has been successfully completed, the patient must take expensive anti-rejection medication for the rest of their life. Their new kidney's life span is unknown, and the body can reject the kidney even after several years of function. The incidence of cardiovascular events and death is highest in the first 3 months after kidney transplantation (Luan 200). Infection, CVD and other comorbidities are responsible for this. Studies have shown that high LDL levels are still present even after transplant (Williams et al. 2006). Diabetic ESRD patients also face possible problems with glycemic control which tends to worsen and is difficult to manage after receiving a transplant (Luan 201).

Each treatment modality has its own extensive set of risks and benefits. Until a kidney can be received, hemodialysis or peritoneal dialysis are the only choices facing individuals today.

1.4.1 Hemodialysis

Invasive techniques, such as access to the blood stream has been historically recorded since the 1600s but hasn't been successful until the early 1960s. During WWII, Dutch physician Willem Kolff was the first to convince industry that there was a future in dialysis (McBride 1989). From then on, large dialysis machines were produced, refined, and distributed across the United States.

The single greatest barrier to the wide use of hemodialysis was that the access to the blood stream could not be maintained over a long period of time (McBride 1989). The 1960s was a land mark decade for technological innovation. It was demonstrated that non-functioning kidneys could be maintained on continuous hemodialysis. A Teflon shunt was created which enabled blood to flow successfully.

Hemodialysis is currently the most popular choice for ESRD patients. The patient travels to the dialysis center three times a week, to be placed on a dialysis machine for three to four hours a session. Time spent on the machine is dependent upon on how much fluid needs to be pulled from the body. The advantages of this procedure can be seen in **Table 2**.

Table 2. Advantages and Disadvantages of Hemodialysis

Advantages	Disadvantages
Nurses and Technician Support	Traveling three times a week
Regular contact with patients, staff	Permanent access; needles
No equipment at home	Restricted diet, fluid intake
Three treatments, four days off	Discomforts such as cramps, fatigue
	Risk of infection

The chart above outlines some of the common advantages and disadvantages that physicians describe to their patients. However, there is a different picture to consider as well. Most patients who are on hemodialysis no longer have the ability to work. Their income therefore must come from another source, such as their spouse or possibly retirement funds. Although Medicare covers the cost of hemodialysis three months after they begin, other costs such as medication, food, and housing naturally are not covered. This will be discussed in later chapters.

Hemodialysis is also harsher on the heart. Depending on whether or not the patient follows their fluid restrictions, their dry weight can be compromised and the machine will end up pulling up to twenty pounds of fluid in one sitting. Dry weight is defined as the lowest weight a patient can tolerate without the development of symptoms or hypotension (Jaeger et al. 1999). This is a very rough process on the heart, especially if the patient already has CVD and other complications. Technological related issues including intensity and rapidity in controlling fluid volume overload and achieving dry weight are very important factors that may induce a rapid and steep decline of RRF both in PD and HD patients.

The day off in between treatments allows for some recovery; however, it is not enough to offset the possibility of cramping, hypotension, and nausea. This does not include the complications of blood clotting, which can result from a faulty fistula.

Hemodialysis is attractive to the elderly. The North Thames Studies is one of the few studies that examined modality choice based on age. It found that patients who were seventy years or older were sixty times more likely to choose HD than those aged between 18 and 40 years, though patients who had received predialysis care were much more likely to choose PD than those who had not (Brown et al. 2010)

Both HD and PD treatments are invasive and require access through cannulation and/or catheters (Duval 2010). Along with all medical procedures, there is risk involved, which can be avoided by proper hygiene. However, some procedures are dependent upon the skill of the nephrologist, nurse, and technicians.

1.4.1.1 Fistulas and Risks

Before a patient can begin HD treatment, a fistula must be surgically inserted into the patient's arm. A detailed vein analysis of the patient will prevent the possibility of collapsed veins. A bovine tube is inserted. It is connected to an artery on one end, a vein on the other. While the fistula normally takes three months to mature before it is stable enough for cannulation (inserting needles into the vein), a catheter will be inserted below the collar bone. There has been a greater dependency on catheters within the dialysis community. The infectious and vascular complications of catheters are well documented (Levine 2008). However, some patients' fistulas do not work correctly or their veins do not carry enough blood volume so the catheter is preferred, even though it is characterized by higher mortality rates.

There has been an increased effort to create AV fistulas, but there are complications that can occur even before dialysis proceeds. The fistula must mature for three months before the needles can be inserted. A presence of a pulse and thrill does not automatically equal adequate fistula function (Levine 2008). Complications are usually discovered when cannulation is difficult or the patient is infiltrated (vein is

punctured and blood flows into the arm). Surgery could be used to correct the situation, or a new vein mapping will be required.

To reduce the possibility of complications, it is recommended that the patient should not place pressure on the fistula, as this could cause thrombosis (clotting). Provider's caution patient's against holding heavy objects, wearing tight clothes and jewelry.

Another possible risk is hyperkalemia, which is an extreme amount of potassium in the blood stream, resulting in an abnormal heart beat which can be fatal if not discovered quickly. Hyperkalemia is seen in about 10% of hemodialysis patients (Ahmed 2001). Patients with normal renal function eliminate only 10% of their daily potassium load through the gut. In patients with chronic renal failure, gut elimination of potassium increases, and may account for as much as 25% of daily potassium elimination (Ahmed 2001). This volume is equivalent of stool production, so constipation becomes problematic for about 40% of HD populations (349). This predisposes patients to hyperkalemia.

1.4.2 Peritoneal Dialysis

Not all physicians in the 1950s were pleased with the treatment outcomes of hemodialysis. They wanted a system that did not require the complicated hemodialysis equipment. Peritoneal dialysis had been described in the past, but the results were not encouraging due to a high infection rate (McBride 1989). Although technological innovation has made PD highly accessible, the United States has less than 10% of patients utilizing home dialysis therapies (Mehrotra et al. 378). Reasons for this vary and will be discussed in the following chapter.

Patients today can choose from two types of PD: Continuous Ambulatory Peritoneal Dialysis (CAPD), or Automated Peritoneal Dialysis (ADP). CAPD uses the peritoneal membrane, the lining of the stomach, as the filter instead of using an artificial kidney such as in hemodialysis. Through gravity, excess fluids containing wastes from the peritoneum drain into a bag, while fresh PD solution dwells in the

peritoneal cavity for four hours. An exchange takes twenty to thirty minutes. This is a cycle that repeats itself every four hours.

ADP is a process that occurs over night. It has the same concept as CAPD, except that a machine performs the exchanges automatically while the person sleeps for 10 hours. This type of dialysis is preferred for people who need to work during the day. The following figure shows the advantages and disadvantages of PD.

Table 2. Advantages and Disadvantages of Peritoneal Dialysis

Advantages	Disadvantages
Independence	Changes, seven days a week
Once a month clinic	Risk of infection
Easy to travel	Storage space for supplies
No needles	Weight gain
Continuous therapy	Permanent catheter

The biggest advantage that PD has over HD is that the therapy is continuous, causing less strain on the heart. Though PD therapy is at least the equivalent to HD therapy overall, survival differences do become apparent when considering subgroups such as age, diabetes and CVD (Stanley 2010). Although it states that an advantage of PD is independence, patients must have the ability to understand how to use the equipment and how to do it in a timely manner. The responsibility of their health is in their hands. To date there are more than 390 articles in the medical literature detailing the benefits of daily dialysis on quality of life for ESRD patients (Lockridge 2004).

1.4.2.1 Catheters and Risks

The catheter is surgically inserted into the peritoneum (abdominal cavity). This is an area that is prone to infection. It needs to be cleaned daily and needs to be kept dry. The occurrence of peritonitis is an important complication of peritoneal dialysis, accounting for significant morbidity and mortality (Nessim 2010). Peritonitis occurs when the peritoneal wall becomes infected. Symptoms include nausea, vomiting, fever, chills, and excessive fatigue. A large observational study found that the use of

double-cuff catheters were associated with a trend towards a lower peritonitis rate than the use of single-cuff catheters (Nissem 2010). Technological advances help limit the threat of peritonitis. However, it is the patients' responsibility to keep their catheter as clean as possible.

1.5 Nutrition

Depending on which course of treatment is chosen, diet and nutrition plays a central role in maintaining kidney function and good health. Nutritional status has invariably emerged as some of the strongest predictors of adverse outcomes in this patient population (Kovesdy 2010). Although maintaining a 'balanced' diet is emphasized, patients are confused about what this actually entails. There remains a contradiction between current health care initiatives supporting healthy eating versus a dialysis diet. For example, whole grains, vegetables and fruits are constantly touted as the superior food choice for overall health maintenance. The dialysis patients are facing a different reality. The following section will outline a series of obstacles that the patient must face in order to meet their dietary challenges. These all depend on the patient's socio-economic status, access to foods and their current RRT levels. It will also show how detrimental it is to combine certain minerals from food, and how they affect the kidney's ability to function.

1.5.1 Nutrition Requirements

A diet that mainly consists of white bread, white rice, red meat, and a limited choice of vegetables and fruits would be seen as somewhat of a nutritionally deficient diet and would not be recommended to the general population. However, as an ESRD patient, this is a reality. A complex array of charts, graphs and illustrations point out which foods a patient can and cannot eat. However, these choices are also contingent on whether there are co-morbidities present alongside of ESRD. For example, for snacks, a chart points out that a handful of jelly beans, popcorn and sherbet are an

exception. However, if the patient is a diabetic, this is no longer an option. At all costs, sugar should be eliminated from the equation.

Table 3. Appropriate Foods for the Renal/Diabetic Diet

Protein	Chicken	Beef	Fish	Eggs
Grains/cereals	White bread	Rice	Crackers	Rice/corn cereal
Fruits/vegetables	Apple	Berries	Grapes	Carrots, celery
Desserts	Jelly beans	Popcorn	Sherbet	Shortbread
Beverages	Root Beer	Coffee, Tea	Mineral water	Sprite

Dark green leafy vegetables, whole grains, dairy products, and an assortment of fruits should be excluded from the diet (including avocados, tomatoes, and bananas) because of their high potassium and phosphorus content. Lack of arginine, glutamine, zinc, vitamin B6, vitamin C, folic acid, and elvocarnitine may all adversely affect various aspects of immune function and could be instrumental in the high infectious mortality seen in ESRD (Kovesdy 2010). Some charts are misleading because they list some foods as an exception. However, that rests upon the current RRT status of the individual and which treatment plan they are on. If the patient is on PD, they have less dietary restrictions than HD. A physician and a dietitian have the responsibility of outlining the proper diet depending on the patient's lab work (**See Table 3**).

Aside from food restrictions, salt needs to be removed as much as possible in the dietary regimen, which poses several problems for patients. First, it is impossible to completely remove sodium from food. There is a common misconception within the dialysis community that salt is only in food if it comes out of a salt shaker. By not salting their foods, they assume that their food is reduced in sodium. Sodium hides in processed food, canned food, and even in eggs (250 mg). A quarter of a teaspoon of salt yields 590mg of sodium, whereas the dialysis patient is usually given the restriction of 1,500 mg a day.

The second problem lies wherein the reason why most patients are on dialysis: the inability to control their hypertension, or type II diabetes. Dietary changes are required for any chronic disease; however, there are many contributing factors of why a patient cannot follow the diet. Therefore, it is even more difficult to alter the eating habits to that of a complex regimented diet.

The inability of the kidneys to function properly, as mentioned in the previous section, describes the process of fluid removal. By eliminating excess sodium from one's diet, the risk of arriving for dialysis over dry weight is minimized because the patient is less thirsty for fluids. For that reason, a fluid restriction is in place so that dangerous levels of fluids do not have to be removed.

One of the greatest challenges of committing to a renal/diabetic diet is that it is expensive and time consuming. Depending on which treatment modality is chosen, most patients do not have the luxury to stay at home and plan out their meal in detail. If the patient is on PD, they still have to work and have other daily responsibilities that could take time away from grocery shopping and cooking. The location of the food also needs to be considered. There are many patients that drive long distances in order to receive HD treatment because they live in rural areas. HD patients are exhausted from treatment and typically take the rest of the day to recover. The time spent on planning meals and shopping could take away from their time when they do not feel sick or feel like a patient.

1.5.1.1 The Role of Macro and Micro Nutrients

The nutritional status of patients at the onset of chronic dialysis therapy is a strong predictor of both their nutritional status during the course of chronic dialysis treatment and their subsequent morbidity and mortality. It is important to maintain good nutritional status in patients with chronic renal failure before their development of end-stage renal disease (ESRD) and establishment on chronic dialysis (Kopple 1998). Phosphorus, potassium, and sodium play an intricate role in treatment management. Maintaining normal serum phosphate levels is important for preventing

renal bone disease and calcification of the soft tissue in people with CKD (Diet 2009). It takes the expertise of a dietitian and nephrologist to come up with an appropriate medication and dietary regimen, depending on complications that the patient is facing.

There is conflicting evidence in medical journals that state the proper amount of protein that should be consumed. Protein consumption is controversial due to the intensive counseling and monitoring required to prevent malnutrition (Diet 2004). In order to maintain an even or positive nitrogen balance, dialysis patients are advised to ingest a daily amount of protein of approximately 1.1-1.3g/kg a day (Kovesdy 2010). This however could be problematic because an excess of protein could lead to early mortality, due to the increase of uremia in the blood stream which the kidneys lack the ability to filter out. Eating less protein may be helpful in reducing blood urea levels; however, protein is needed to maintain muscles, aid in building resistance to infections and repair and replace body tissue (Wisconsin Nephrology 2011).

Due to the difficulty of maintaining adequate energy intake on low protein, low potassium diets, patients may tend to rely more on food sources containing high amount of fat (Kovesdy 2010). Again, socio-economic status plays an important role. Phosphorus binders are required to be taken when eating foods. The binders work by binding to phosphorous and is excreted through stools. The binders alone cost upwards of \$2,300 a month, and are not covered by Medicaid. The binders plus the cost of food could dissuade the patient from making proper choices. However, if the diet is not accompanied by careful planning and supervision to assure that the macronutrient content of the patient's food choice is appropriate, unintended consequences could occur. Higher protein intake can result in increased potassium and phosphorus intake with resultant increase in the serum levels of these elements (Kovesdy 2010)

End Stage Renal Disease is a complicated chronic disease that affects patients at different levels. Each person has a unique way of managing their illness, which may or may not comply with the provider's recommendations. This is due to various reasons and will be explored in later chapters. Treatment for ESRD requires effective communication between the provider and patient, resulting in adherence to medical

advice, follow up treatment, self-directed care, and maintenance of a strict dietary protocol. The next section will discuss the importance of patient comprehension and provider care.

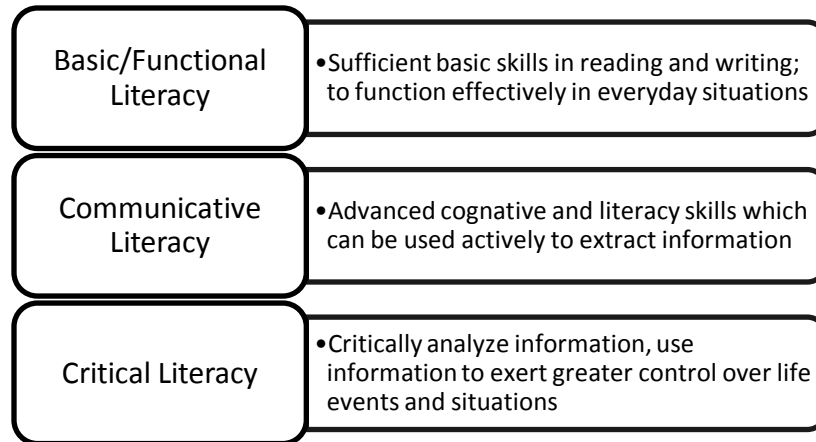
1.6 Health Literacy

Health literacy (HL) is defined as the ability to comprehend basic health information required to function successfully as a patient (Gazamararian et al. 2003). Roughly 48% of adult patients in the United States lack HL skills to fully understand and act upon medical instructions (Wolf 2005).

Studies have repeatedly shown that inadequate HL contributes significantly to a widening chasm between patient comprehension and provider care, which results in negative health outcomes and contributes significantly to rising health care costs (Gazamararian et al. 2003). A study done by Davis et al. (2006) found that almost half (46.3%) of patients misunderstood one or more of the prescription label instructions, and the prevalence among patients with adequate, marginal, and low literacy was 37.7% (890)

Three types of health literacy have been noted (See figure 3). The most commonly researched is functional health literacy, which is a measure of a person's capacity to function in the health care setting as determined by literacy and numeracy (Schillinger et al. 2003: 85). Communicative and critical health literacy require advanced skills to critically analyze information and use information to exert greater control over life events and situations (Ishikawa 2009: 518). As of today, 48% of adults within the United States lack the reading and numeracy skills required to fully understand and act upon instructions given by their health care providers (Wolf 2005: 1946). Other studies have demonstrated that patients recall and comprehend as little as 50% of what they are told by their physicians (Schillinger et al. 2003).

Figure 3. Three Types of Health Literacy



1.6.1. History of Health Literacy

Literacy has been a national priority since the early twentieth century. Programs initiated during the 1960s, such as the War on Poverty, expanded basic education so the average adult could receive an 8th grade education. In 1970s, it was deemed necessary to have at least a high school degree. As each decade progressed, more sophisticated definitions, conceptualizations and measurement began to evolve in large part because military and labor experts were interested in determining what individuals needed to function on the job (Berkman et al. 2010).

During the 1980s there was a turning point in which literacy affected public policy. A study by Carroll and Chall identified low literacy as a “national policy concern that would limit our economic, social, and defense competitiveness” and “risk the very security of our nation” (Berkman et al. 2010: 10). Due to various definitions of literacy, the government created the National Literacy Act which defined literacy in 1991 as “an individual’s ability to read, write and speak in English, to compute, solve problems at a level of proficiency necessary to function on the job, achieve one’s goals and develop one’s knowledge and potential” (Nutbeam 2000).

The NAAL was the first large scale national literacy assessment to contain a component specifically designed to measure health literacy in U.S. adults (Berkman et al. 2006). The findings collaborated with the Institute of Medicine estimation that 90 million adults in the United States may have trouble understanding and acting on health information (Davis et al. 2006). Health tasks were characterized into three types: clinical, preventative, and navigation of the health system (Berman et al. 2010). The United States has shifted from an agricultural, industrial, and now to an information based economy. A greater emphasis of preventative care and self management skills is placed on the individual. The practice of quality control over medication use is becoming more the responsibility of the patient and less the responsibility of the provider (Davis et al. 2006).

1.6.2 Chronic Disease and Health Literacy

Patients with low health literacy and chronic diseases, such as diabetes, asthma, or hypertension, have less knowledge of their disease and its treatment and fewer correct self-management skills than literate patients (Gazmararian et al. 1999: 545). A study conducted by Ishikawa found that patients with low health literacy and type II diabetes were more likely to use their physicians as the sole source of medical information and less likely to seek information from other sources (Ishikawa 2009: 522). This is an important point to consider, for the American public has been shifting from predominantly acute, episodic therapy to long-term treatment of chronic conditions (Kopyt 2006: 133). The providers are the crutch of the health illiterate, which may or may not guide them around the pitfalls of chronic disease.

The research conducted over the past thirty years has been specifically focused on health literacy with regard to chronic diseases such cardiovascular disease and type II diabetes. Research concerning the relationship between health literacy and end stage renal disease (ESRD) is extremely limited. Many physicians' and their patients remain unaware of the diversity of clinical characteristics of renal disease, and chronic kidney disease (CKD) in its earlier stages often shows no symptoms and has received scant attention

(Kopyt 2006: 133). The relationship between chronic disease and HL is complex to the extent that an individual's literacy skills govern the ability to act upon instructions, understand the implications of their disease and, access health services.

A study by Schillinger et al. audio recorded the interaction between providers and diabetic patients. When asked by physicians to restate or interpret new concepts, patients responded incorrectly 47% of the time (e.g. failing to recall, misinterpreting the new concept, or stating health beliefs that could interfere with the integration of the information) (86). The study found that physicians ensured comprehension of medication changes only 13% of the time (87). A similar study reaffirms the latter. Physician-patient communication is one of the key elements to promote shared understanding of goals and strategies for self-management (Parchman et al. 2009).

The prevalence of low HL, especially among the elderly, ethnic minorities, and socio-economically disadvantaged suggests that problems with health communication may contribute to disparities disproportionately (Schillinger 2003). For example, Johnson and colleagues found that physicians were 23% more verbally dominant and 33% less patient-centered in their communication with African American patients compared to white patients (Parchman et al. 2009).

In regards to the different studies and information presented, it can be acknowledged that low health literacy affects individuals from across a broad spectrum of backgrounds. As the nation is changing from acute to chronic care, HL is a tool that is necessary within this information-based society. While it is difficult enough to contend with type II diabetes, the consequences of failed kidneys adds an extra layer of self management skills with which individuals may or may not be equipped.

Anthropology has a long standing history of contributing to the ongoing discussion of doctor-patient relationships in a theoretical context. To move beyond discussion and forward to application, critical medical anthropology (CMA) focuses attention on emphasizing structures of power and inequality in health care systems and the contributions of health ideas and practices in reinforcing inequalities in the wider

society (Singer et al. 2007). Health literacy, ESRD, and patient provider relationships co-exist under an umbrella of economic policies which are dictated by neo-liberal values. Singer states, “People develop their own individual and collective understandings and responses to illness and to other threats to their well-being, but they do so in a world that is not of their own making (2007).”

Anthropological analytical approaches such as CMA and EM strive to unveil discrepancies which could further negatively impact patients’ health outcomes.

The patient’s stance as a modern citizen in a neoliberal environment is a prominent theme in today’s literature. The following chapter will explore the physician’s role within the political-economy of health-care, which will reveal additional challenges that both the provider and patient face in order to overcome health disparities in the ESRD population.

CHAPTER 2: The Political-Economy of Health Care

2.1 The Neo-Liberal Dilemma

Current issues regarding medicine cannot be fully understood without contextualizing changes in the profession within broader trends towards globalization, a general increase in the power of corporations, the rise of neo-conservatism, and a decline in the relative autonomy of the state (Coburn et al. 378). The structural barriers that health care providers face are undeniably tied to economics. For example, changes in technology and power dynamics have contributed to altering the way in which the provider cares for the patient. In this chapter, I will discuss neo-liberalism in light of current Medicare policy and its relation to ESRD. I will analyze the notion of a “health care provider” within this context and critique the homogenizing notion of the provider. In doing so, I will examine the interplay of the power dynamics between not only the providers and the patient, but the providers and the system.

2.1.1 Neo-liberalism and ESRD

The last half-century has witnessed the growth of consumerism, the movement dedicated to fulfilling and protecting the rights of consumers (Buetow et al. 2009). This has largely been in part of an abrupt change in economic policy in the 1970s. It brought a series of changes that are beyond the scope of this discussion; however, the change in economic policy reconstructed the values and the priorities of the individual. While personal and individual freedom in the marketplace is guaranteed, individuals are held responsible and accountable for their own actions and well-being (Harvey 65).

Neo-liberalism is defined in a way that individual successes or failures are interpreted in terms of entrepreneurial virtues or personal failings (such as not investing significantly enough in one’s own human capital through education) rather

than being attributed to any systemic property (such as class exclusions attributed to capitalism) (Harvey 66). One of the problematic aspects of this system is that it leaves out a significant section of society that lives at the social or economic margins. During the past five years, the number of uninsured Americans increased by more than six million, rising from 39.6 million in 2000 to 46.1 million (nonelderly) in 2005 (Dubay et al. 2005). The current health care cost situation in the United States is extremely high, and it is predicted that costs are going to escalate. The National Health Expenditure has risen from \$73.2 billion in 1970 to \$1.04 trillion in 1996 (Peter et al. 2004).

In the 1960s, care of the ESRD patient changed through technological innovation and financial support through Medicare. Prior to the first hearing concerning the ESRD Medicare program in 1975, a committee was expected to review patients in need of dialysis and decide if they could receive dialysis. The primary concern was to regulate the use of an expensive medical treatment such as hemodialysis (Lockridge 2004). The ESRD amendment of 1978 developed a cost-reimbursement structure that would create incentives for more efficient delivery of ESRD services. The number of patients on Hemodialysis was becoming a burden, so the outcome of the composite rate would provide patients 100% coverage on day 1 if they chose peritoneal dialysis, whereas hemodialysis would be covered after 3 months. In 1981, a reimbursement plan was established so that private insurers would provide the first 12 months of primary coverage, reducing costs to the Medicare program (126). The composite rate in 1983 was set at \$130, which bundled the dialysis treatment, lab work, and other billable items together.

Since 1983, various amendments were added, which significantly altered the types of medications and lab work that patients could receive under Medicare. For example, in 1989 the reimbursement rate for erythropoietin (EPO) --a product that is used to stimulate the production of red blood cells--was set at \$40 for less than 9,999 units. By 1994, the law lowered EPO reimbursement to \$10 per 10,000 units. As reimbursements were lowered, the cost of dialysis was increasing. In 1973 there were

approximately 11,000 patients on dialysis, with 40% of them performing peritoneal dialysis. This is then compared to 2,000,000 patients on Hemodialysis, and about 10% on peritoneal dialysis in 2002 (Lockridge).

The decreasing numbers in funding of the rising costs of dialysis (which costs roughly \$12,000 a month) creates a troubling question. Has the social safety net been reduced to a bare minimum in favor of a system that emphasizes personal responsibility? Social scientist David Harvey notes:

“As the state withdraws from welfare provision and diminishes its role in areas such as health care, public education, and social services, which were once so fundamental to embedded liberalism, it leaves larger and larger segments of the population exposed to impoverishment” (Harvey 2005; 76).

It is then safe to assume that the larger segments of the population exposed to impoverishment have less access to healthcare and to basic needs (food and shelter). Without basic needs met, it is impossible to navigate the landmines of the health care system which require the patient to have high HL skills.

2.1.1.1 Cost Containment in Dialysis

The private sector of dialysis constitutes the majority of dialysis centers in the United States. Fresenius Medical Care is the largest provider of dialysis services in the world. In the U.S. and Puerto Rico, there are 1,083 facilities and over 79,000 patients (Bucklelew et al.2003). There have been ongoing debates about quality of care and mortality in for-profit dialysis centers. These debates have been mostly dispelled (Lee et al. 2010), yet for-profit centers continue to be highly economically driven and cannot offer medial services such as providing blankets, lab work, and other extras that not-for-profit dialysis centers can afford. A recent study demonstrated that patients treated in for-profit dialysis tend to have higher hospital days per year because the cost of any interventions that prevents lengthy hospital admissions is greater than the financial rewards from avoiding missed treatment (Lee et al. 2010).

Based on a large study, Peter et al. (2004) evaluated costs in a representative United States cohort of 109,321 elderly patients initiating dialysis therapy. The study found that CKD costs peaked in the months immediately before and after initiation of dialysis, which was exacerbated by a rise in hospital stays (Peter et al. 2004). Other studies show similar results that early detection of CKD can prevent the onset of ESRD, lower the need for dialysis, and reduce costs (Kopyt 2005).

Preventing non-dialysis related injuries, infections, conditions (e.g. co-morbidities) can lower hospital stays. Patients from socio-economically disadvantaged backgrounds, i.e. those who have limited or no access to transportation or the ability to see their primary care physician, are at risk for not receiving non-dialysis related injuries that will inadvertently affect their treatment or even cause death. Before recent changes in Medicare bundling, labs (blood work) could be drawn for patients that were not necessarily dialysis related. Ailments that could result in hospitalization (which would drive up costs for Medicare) could be treated and prevented before the onset. However, this no longer is an option. Each order received from a dietitian, physician, or an outside party needs to be properly coded, or else Medicare will not pay. The rise in restrictions has constrained the capacity to which the physicians can provide for.

It is too early to assess how patient quality of care has been transformed by Medicare bundling. However, it is apparent that large private dialysis corporations are crippled under the burden of providing care for an ever-growing population. It is claimed that privatization and deregulation, combined with competition eliminate bureaucratic red tape, increase efficiency and productivity, improve quality, and reduce costs, both directly to the consumer through cheaper commodities and services indirectly through reduction of the tax burden (Harvey 65). However, this is not the case according to a recent panel presentation by the president and CEO of Gambro Healthcare/U.S., and the presidents of DaVita and Fresenius. A variety of issues complicate and hinder the ability of the private sector to provide better care, which mostly involves funding.

Labor costs associated with dialysis require the majority of funding, which rests upon the distribution of costs per treatment. While hospitals (not-for-profit) dialysis centers receive a 2% increase a year due to inflation, for-profit centers do not. According to Buckelew, CEO and President of Gambro Healthcare, “We can’t afford to not have excellent caregivers, and yet, financially, we can barely afford it (2003).” Nurses that enter dialysis with no previous experience need to be trained. This is true for the technicians as well. Nursing costs have nearly tripled over the past 10 years, including salary and bonuses. The RN bonuses that were paid out in 2002 totaled \$2 million, which was a 40% increase in 2001 (Buckelew et al. 2003).

The biggest competitors are hospitals because they have a larger budget and are compensated differently (Peter et al. 2004). Nurses and technicians gravitate towards not-for-profit dialysis services because there are less chairs (some units have up to 24 chairs per shift) and less rotations. According to Buckelew, it could also be because “the dollar is too compelling (2003).” The growing demands for cost containment and market discipline have limited the autonomy of both physicians and patients (e.g. Medicare) (Tomes 2007), and will continue to do so unless a solution can be devised.

Inadequate HL can contribute significantly to the rising health care costs. The costs of managing consequences of poor adherence to medication alone are excessive and have been estimated to be greater than \$100 billion yearly (Dunbar-Jacob et al. 2001: 57). A vicious cycle is now in place: Medicare’s budget is shrinking to combat rising health care costs, the patient has no additional resources; yet they are contributing to the rising health care costs because they do not have the resources (HL, socio-economic status) in order to play the role of a responsible, rational consumer. According to the physician, what is a responsible, rational consumer?

2.1.2 The Modern Patient

As more occupations have become professions in the so-called ‘informational societies’ of the Western world, proportionately more patients have become

‘modernised’ (Buetow et al. 2009). Demands for more patient empowerment have been strong enough to be included in statements on international health policy, e.g. the declaration of the Ottawa Charta by WHO in 1986, which outlined patient empowerment and self-determination as important goals of health promotion policies (Dieterich 2007: 279). The emergence of the ‘*modern patient*’ is testament of the belief that patients are entitled to and can exercise control over their health decisions. According to Beutow et al. (2003), the term ‘modern’ patient is elusive and difficult to pinpoint the exact meaning of what being modern really means. Modernity is culturally constructed and is not static. Concerning the doctor-patient relationship, the comparison between modern and non-modern within a neo-liberal society creates a guideline for what is acceptable for how a patient should act and exercise their responsibilities.

According to Dieterich (2007), the *modern patient* is someone who is responsible, rational, well informed, and able to contribute to the balance of market powers. This patient is supposed to be a partner to the physician, leading their lives not through obedience but through rationality. The *modern patient* resembles the modern citizen and therefore represents ideas of adequate civil behavior within the framework of health care (Dieterich 2007: 284). The physician, although now an active partner, is still in control. Power and knowledge are intertwined but allows for the *modern patient* to take a part of the role of the doctor, both by co-providing formal health care and by providing educated self-care, i.e. in chronic disease management (Buetow 2009: 97).

With the advent of the Internet, research and information is easily accessible and encouraged. Welsh-Cline advocates that ‘consumers’ (i.e. patients) need to become more media literate, aware of and understanding the subtle yet influential messages embedded in drug advertising, websites, and complementary and alternative medicine (2003). While the responsible patient is praised, it is as easy to slip over the invisible boundary to become a difficult patient. Evidence-based medicine has gained great popularity as the new scientific gold standard, a standard seemingly protected both

from bad science and undue commercial influence (Tomes 2006). If too educated, stubborn, probing, or questioning, the patient becomes a hindrance. Ignorant, irrational patient-consumers provide an easy explanation for the persistence of problems within the health care system: they refuse to believe in the truths revealed by science or economics. They resist paying what services are worth, seek the wrong services (botox), and ignore the prudent action (healthy diet) (Tomes 2006: 698). The images of difficult, well informed or demanding patients illustrate the concept of the insatiable consumer whose overflowing desires sometimes have to be limited by physicians in the interests of rational care (Dieterich 2007).

There is a plausible reason for the increasing numbers of ‘difficult patients’. According to M.S. Henry, it is the physician’s failure to disclose uncertainty concerning standard of care that has increased the responsibilities of the patient. Uncertainties involved in diagnosis, prognosis, and treatment have rarely been acknowledged in modern medicine (Henry 2005), for there is a fear that an admission of uncertainty will discredit the medical profession. Uncertainty and trust are intertwined. If the patient feels that there isn’t adequate communication and trust, second opinions will be sought after.

While physicians have a series of expectations for the patients, the same is true for patient expectations of the physician. Where previously people were prepared to accept long waiting times and poor communication from public services, many now demand to be treated quickly, politely and effectively (Neuberger 2000). Physicians are increasingly aware of the need to satisfy patients. According to Dieterich,

“Physicians characterize themselves as personal partners of their patients, whose needs and wishes they are willing to fulfill...it is openly discussed that physicians have to justify themselves and appeal to patients in order to stop them from abandoning medical care (Dieterich 2007: 281).”

There is also a threat of physician reviews from patients. “The trend toward pay for performance is increasing and that refusing to participate will result in the loss of business from the entire employer coalition (Safran et al. 2005: 60).” This could

also result in malpractice. A source concluded that there are more than 125,000 cases against physicians in the US courts on any given day (Henry 322).

The physician's perspective of the patient is crucial to understand in not only from a neo-liberal perspective but also from a perspective of health literacy. Literature today has produced physicians that, as shown, require active participants willing to learn and act for their personal health, and are responsible. The pertinent question is: how can a patient be *modern* if they do not have the health literacy skills?

2.1.3 Doctor-Patient Relationships

Issues of power and control in the doctor-patient relationship were central to the socio-political critiques of medicine; particularly the feminist critiques of medical patriarchy that reached their zenith in the 1970s (Mead et al. 2000: 1089). Physicians were seen as partially responsible for patient's non-compliance and dissatisfaction with their treatment. In light of this, medical schools began to advocate a 'patient-centeredness' approach, which is an attempt to understand patients' illness and their needs from their doctor.

There is a lack of agreement concerning the exact meaning of 'patient-centeredness' and its effectiveness as a communication strategy. Some studies found that patient-centered consulting does not significantly improve patient-satisfaction or other outcomes (Mead et al. 2002: 296; Mitchie et al. 2003: 204; & Mead et al. 2000: 1089). On the other hand, some studies found that the match between the physician and patient with respect to the explanatory model of illness and expectations for the visit are equally important in determining health outcomes (Cooper Patrick et al. 1999: 583). However, the methods used to define and measure outcomes remain firmly in specialist hands which are generally collaborations between researchers and clinicians, not physicians and patients (Tomes 2006). The results gathered from these assessments may not capture what the patients find most important. The patient then

becomes a fixed object with a series of inferred expectations which may not fit easily fit into the model of rationality assumed by the evidence-based medicine approach.

Critics have pointed out that a participatory decision-making style of the patient centered approach is an assumption that patients have the health literacy to engage in this process (Dieterich 2007, Gazmararian et al. 2003, Tomes 2007). It is also assumed that patients are both linguistically and culturally equipped to engage in a discussion with their doctor about diagnosis and treatment (Hamilton, 2009: 163). This assumption is supported by the Medical Expenditure Panel Survey, which found that only 58% of patients reported that their health-care provider's explained terminology in an understandable way (Koch-Weser 2009: 371).

These assumptions of the participatory decision-making style align neatly with the ideal *modern patient*. It is vital to understand that the *modern patient* is a homogenizing term that expects the patient to be well educated, to have a strong socio-economic background, to be health literate, and most likely to be a white man. It does not take into account the complexities of patient-physician relationships and the different biological and cultural realities that each possess. In that respect, a patient-centered approach could be considered homogenized as well, since theoretically the doctor brings a series of expectations to the clinical visit with the same goals in mind for each patient, regardless of their background.

These notions have been challenged and dissected to reveal potential issues in which the physician can improve, such as identifying their own personal racial biases (Cooper-Patrick et al. 1999), their perceptions of illness and disease (Kleinman 2006), and their lack of awareness of a mismatched set of expectations. A study done by Cooper-Patrick and colleagues revealed that African Americans had significantly less participatory visits than whites (1999). A potential solution to this problem would be to create 'interventions that empower ethnic minority patients to become more informed and active consumer of health care' (588).

Globalization has created a series of challenges for physicians to tailor their visits depending on what minority they are treating. Cultural competency classes and

workshops give the provider a foundation for understanding and communicating with different cultures. By understanding a cultural viewpoint of medicine and illness, the physician can then find a way to positively communicate their concerns, which will reduce error and non-compliance. The physician has to play the role of a cultural informant so the patients can acquire the necessary health literate skills in order to participate in a supportive patient-physician relationship.

Amid the excitement, hustle and bustle of churning out articles outlining patients rights, responsibilities, power, and creating an ‘informed health consumer’, an important question arises. Is this what the patient wants? Do they want to be responsible for their health or would they rather follow the paternalistic style of medicine? And more importantly, is too much responsibility being placed in the patients’ hands?

An informational article written by John Hamilton questions the extent to which there is a universally appropriate model, or whether doctors need to be equipped with multiple models to accommodate cultural and other differences in their patients. An example about Malaysian patients and physician expectations revealed a gap. The doctor’s participatory-decision making approach was confusing to the patient because they were expecting that a doctor would simply select the most appropriate treatment for them and initiate it. A consultative, collaborative process was not expected and in this instance not valued (Hamilton 2009). Deborah Lupton makes a similar point by discussing Good’s findings of comparing the practices of French and American physicians treating patients with HIV/AIDS. IN France, she found a more paternalistic model of the doctor-patient relationship in which trust is privileged, accepted, and supported by both patients and doctors (Lupton). This is naturally contrasted by the American model of patient empowerment.

In order to understand whether the patient values a paternalistic approach over a patient-centered approach, an evaluation needs to be performed within the clinical encounter. Issues that need to be addressed include contributing factors such as health literacy, socio-economic status, and perceptions of health and illness before a

successful treatment can be established. The patient, a once assumed one dimensional, passive entity has now turned into a three dimensional puzzle.

To unlock the patient-provider relationship, anthropologist Arthur Kleinman has come up with the Explanatory Model, which places doctors and other clinicians in a position to negotiate conflicting views of illness beliefs and therapeutics which engage patients' trust (Lazarus). It is clear that the patient-provider relationship cannot be analyzed from one clinical encounter; the very system in which the clinical interaction exists in must be analyzed from a macro perspective. One such perspective is clinical medical anthropology, which recognizes that health itself is a profoundly political issue, while acknowledging on-the-ground features of social life, social relationships, social knowledge, as well as with culturally constituted systems of meaning (Singer 1995:81). Both approaches are essential in contextualizing the physician's shared experiences within structure, hierarchy, and power.

2.1.3.1 Explanatory Model

An 'Explanatory Model' refers to the beliefs and expectations, norms and behavior, meanings of health and illness, and therapeutic activities and evaluation of outcomes embedded in a person's cognitive system and general culture patterning (Lazarus 1988). Kleinman (2006) who is largely credited with his perceptions of the EM, distinguishes bio-medicine's view of disease versus the patients' lived experience of illness; i.e. cultural factors governing perception, labeling, explanation, and valuation of the discomforting experience. The remedies prescribed by physicians may fail to cure disease, despite effective pharmacologic action, when patients fail to follow through on the medical regimen because they do not understand (or do not agree with) the physician's stated rationale for their actions (Kleinman et al. 2006).

Discrepancies between expectations of patient understanding and care will yield unintended consequences such as inadequate or poor care. Kleinman (2006) advocates that anthropologic and sociologic studies should be utilized within medical schools and applied in clinical settings with the goal of training the physician to elicit

the EM with a few simple and direct questions. This will eventually lead to identifying contradictions and conceptual differences which will help the patient and doctor enter into a negotiation toward shared models and analyze them in relation to expectations and therapeutic goals (Kleinman et al. 2006). The teachings will also offer ethnographic accounts of cross-cultural studies which will help foster an understanding of clinical realities as being culturally constructed. Accounts of healing beliefs and practices in other cultures will alert health professionals to patient and family views of clinical reality and encourage understanding of those views (Kleinman et al. 2006: 148).

Explanatory models are different for each person; their cultural realities of disease and illness develop their perceptions of biomedicine. Explanatory models are flexible, not static. Kleinman utilizes examples of cultural traditions that clash with the biomedical paradigm, which furthers his argument that a poor medical encounter is the result of ignorance to perceptions and cultural beliefs. However, misinterpretation of what the physician prescribes or diagnoses can occur as well, which frequently happens outside the doctor's awareness and can result in marked distortion of the doctor's explanatory model and the treatment regimen prescribed (Kleinman et al. 2006: 145). This can happen for a variety of reasons, including health literacy, economic status, perceived notions or cultural beliefs.

2.1.3.2 Explanatory Models of Physicians

To gain a better understanding of the patient-provider relationship, the provider's explanatory model must also be acknowledged. According to Hahn, not only is the work of medicine transacted through a complex of regular, rule following, and ritual social interaction, but the bio-medical social system is reproduced, taught to newcomers by means of partly overlapping social relations known within this system itself as medical education (Hahn et al. 2003). Thus, the physicians' explanatory models are replaced by a standard, shared set of assumptions and rules of conduct based on the scientific method (Lazarus 1988). It can be argued that medicine draws

individuals with strong science backgrounds which could contribute to their ability to conform to the culture of bio-medicine.

The physician's explanatory models are shaped by their position within the medical community as well. Within each branch, higher status is granted to the heart, than to the kidneys or digestive tract, corresponding in part to the cultural symbolism of these body parts. Financial and other symbolic rewards generally accord with these divisions as well as with the use of high technology (Hahn et al 1996). Generally, a surgeon has less patient contact than a primary care physician, so their perceptions of care may be drastically different. This hold true in the dialysis community as well. The direct link to patient contact is not the nephrologist, but the dialysis technician and nurse. Their perceptions of care are not linear, and will be explored further in Chapter 4.

The explanatory models that were collected from the physicians at Good Samaritan Hospital support this. When asked if their cultural background influenced their training, the answer was immediate: "None whatsoever. My education and training are solely based on Western medicine." Their views of their patients were homogenous as well, claiming that "patients are the same. They have the same disease. They are very much similar" and "there are no different cultural perceptions of medicine. People react to their disease about the same." The physicians in this sample are not North American; they all come from different regions of the world. Is bio-medicine that static that the physician's own cultural perceptions of medicine are erased and replaced by the views of biomedicine?

According to Deborah Lupton (2002), medical knowledge is just as subject to change and variation as are other systems of knowledge, including lay knowledge. Comparative analyses of medical discourses and practices in different cultural settings often reveal the strikingly different ways in which the same knowledge system is understood and practiced (Lupton 2002). The example that was provided shows the differences in communication styles that American doctors practice versus that of Japanese doctors. American doctors inform their patients more quickly about their

disease than Italian and Japanese doctors. American doctors regard patient autonomy as important, whereas Japanese and Italian doctors follow a paternalistic and protective model of care and are less supportive of the notion of patient autonomy (Lupton 2002). It is evident then that bio-medicine can be altered by the values that society places upon the system.

Expectations of doctor-patient partnerships have been complicated not only by persistent asymmetries in the knowledge and power bases of the two participants but also by contradictory pressures to limit costs (Tomes 2006). Although Kleinman's EM is revered as “instrumental in drawing attention both to the importance of incorporating people's knowledge of illness into therapeutics and to the biomedical model that permeates Western Medicine” (Singer 1995: 85), it is important to go beyond patient-provider relationships and look at the system wherein these relationships function.

2.1.3.3 Critical Medical Anthropology

Medical anthropology recognizes the fundamental importance of biology in health and illness. However, medical anthropologists generally go beyond seeing health as a primarily biologic condition by seeking to understand the social origins of disease, cultural construction of symptoms and treatments, and the nature of interactions between biology, society, and culture (Singer 2007). Critical Medical Anthropology (CMA) has in part risen out of the dissatisfaction of narrowly explaining health-related beliefs and behaviors at the local level in terms of specific ecological conditions, cultural configurations, or psychological factors (Hahn et al. 2003).

Societies do not function independently from each other. Phenomena that are occurring at a local level could be the result of larger, global forces. Therefore, a macro-perspective is needed to inform the conclusion that was reached at a micro, local level. For example, the political economy is a force that must be included in a discussion concerning health literacy, ESRD and patient-provider interactions because

it is impossible to separate the undue political and economic influence from medicine. Individuals from a lower socio-economic status may not have the same opportunities for a higher education than individuals coming from a higher socio-economic status. Health disparities and a lack of access to resources (i.e. education, health clinics) could compound their situation, resulting in lower HL levels. Singer acknowledges the importance of the EM, argues however that structural factors prohibit the type of open communication and collective decision making that the Kleinman model posits (Singer 1995: 85).

Applied anthropologists believe that science does not exist in a social vacuum, and that its fundamental purpose is to apply its findings to solving human problems and to improve the quality of human life (Singer 2007). Critical medical anthropologists believe that theoretical discussions in academic circles, scholarly fields, and conferences are not useful unless applied in actual clinical settings.

Merrill Singer advocates for a system challenging praxis, which essentially means unmasking the structural roots of suffering and ill health (Singer 1995). These 'structural roots' could refer to policies or economic decisions that could adversely affect marginalized societies, which is also an emphasis of CMA. A critical medical anthropology approach in focusing on social relationships brings attention to issues of noncompliance, dissatisfaction, and poor communication (Lazarus 1988: 47). These all relate to quality of care issues which are exemplified in patient-provider relationships.

Lazarus has suggested that the EM and CMA approach should not be used in isolation. By only solely concentrating on eliciting and interpreting patients' EMs, the study is forced away from a critical evaluation of the physician's own role in the interaction. The EM of the provider allows for their perspectives to be framed within the biomedical system in which they function in, where set rules and regulations govern their activities. This in turn allows for a critical medical anthropological approach to analyze the provider within the dialysis center. This could potentially contribute towards a system

challenging praxis which will strive to heighten social action towards an improved understanding of the provider's perspective of health literacy.

Lazarus (1988) also suggests focusing instead on interactions within institutions, which serves as a bridge between EM and CMA approaches. The clinical setting is not merely a backdrop for interactions but is an integral part of the doctor-patient relationship, helping to determine how people act and how much power the physician sustains (Lazarus 1988). For example, this can be seen within the dialysis center. The managers of particular medical institutions make decisions, often based on considerations of time and money that affect the conditions under which doctor-patient interactions take place (Lazarus 1988). Medicare's changes in policy and reimbursement also impede on quality of care. The physician must now choose who can receive certain doses over another individual. Whereas medications were freely dispersed throughout dialysis patients, physicians have less autonomy on who the medicine should go to, for Medicare has strict protocols governing medicine distribution.

To fully make the connections between the patient-provider relationships within the institution itself in relation to political economic forces is beyond the scope of this study. However, it is important to acknowledge the multiple factors that could potentially hinder a patient-provider interaction. This will be further discussed in Chapter 4.

CHAPTER 3: METHODS AND ANALYSIS

This study uses both qualitative and quantitative analysis methods within a clinical setting, including both interviews and the S-TOFHLA health literacy test. Data collection for this research took place at the Good Samaritan Dialysis Center in Corvallis, Oregon. The qualitative component of the study includes individual interviews, which gives comparative data of the provider's perceptions of health literacy and also ensures a better understanding of the provider's role in the dialysis center. This method, when conducted properly, is also efficient and uses potentially scarce informant time to elicit the most essential responses (Bishop 1999: 99). This is particularly important in the medical field, for providers are under considerable time constraints. The S-TOFHLA will be utilized as a quantitative measurement; it determines the health literacy level of each participant. The interviews, coupled with the literacy test results, will reveal the relationship between perceived and actual findings of health literacy levels within the dialysis community of Corvallis Oregon.

3.1 Research Design

This study seeks to understand the relationship between health literacy among End Stage Renal Disease (ESRD) patients and its relevance for communication between patients and providers. The appropriate paper work was completed through the IRB (Institutional Review Board Approval # 4703) of Oregon State University. Additional steps were required once Samaritan Dialysis Center agreed to facilitate my internship. I completed the online orientation that consisted of reviewing policies and trainings, signed a confidentiality statement, provided immunization records, and became certified through HIPAA training. HIPAA protects the privacy of individually identifiable health information.

My internship began in November 2010, and research continued until the end of June 2011. The data collection process can be seen for both patients and providers in **Figure 3 and 4**.

Figure 3. Phases of Data Collection for Patients

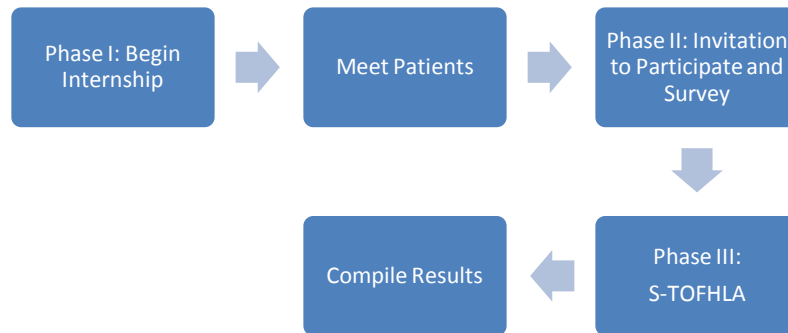
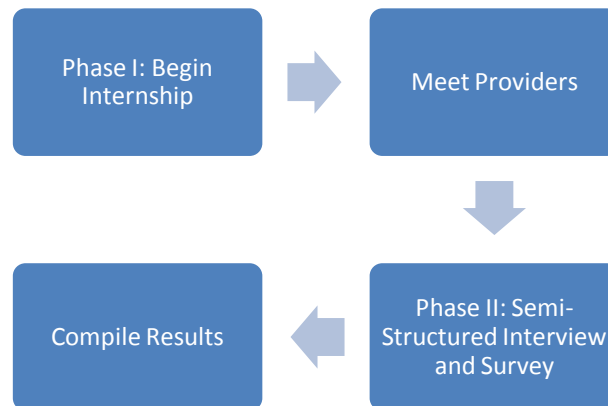


Figure 4. Phases of Data Collection for Providers



3.1.1 Patient and Provider Participation

My internship experience was strictly non-research in terms of participant observation. As previously discussed, in order to collect the data I had to establish the trust of the patients and providers. I spent the first few months talking to patients, meeting providers, and observing interactions. The patients were notified of the research topic through one of the nurses at the dialysis center. The process of self selection was utilized because it was the best way to ensure that the patients were properly informed about the study and given the choice to participate or not to

participate. At the same time, this is a limitation. For example, if a patient has low HL, they may not be as willing to participate in fear of revealing their inadequate health literacy. This could significantly alter the overall group test results. Some patients that are too sick to participate could also be at a higher risk of having inadequate HL, therefore also altering the results.

It is also natural to be subconsciously drawn to patients that look alert and well. The nurse, knowing which patients were at the proper mental capacity to participate, may have excluded some patients because of uncertainty of their willingness to participate. This error can be excluded because the patients that did not participate (according to their chair rotations) were either too ill, mentally unsound, or did not have the ability to speak English. Neither patients nor providers were restricted to any gender or ethnic groups. The goal of the study was to obtain forty willing patients; however, thirty participated. Out of the patients tested, thirteen were peritoneal dialysis patients, and twenty five were hemodialysis patients.

To obtain a total sample of providers within the dialysis clinic, the inclusive sampling technique was used. This enabled me to obtain a total sample of providers in the dialysis clinic. Twenty providers, including nephrologists, physician assistant, nurses, a dietitian, a social worker, and two office workers participated in the study.

3.1.1.1 Informed Consent

Before beginning the interviews, potential participants were given an informed consent document to read and sign. I verbally encouraged participants to ask questions if they required clarification on anything written in the informed consent document. The same consent process occurred for patients taking the S-TOFHLA health literacy test. Willing participants signed a copy of the form for my records and were given an additional document to keep. The informed consent documents for interviews and S-TOFHLA tests indicated that participants could withdraw their interview text or health

literacy test for evaluation at any time prior to publication with no penalty by contacting the researcher listed on the informed consent document.

None of the patients had any trouble understanding the consent process. I made sure that the participants understood the consent form by asking them questions about the study and if they had enough time to participate. Prior to each interview and test, it was made clear that the confidentiality of the information presented was pertinent to the successful outcome of the project.

3.1.2 Interviews and Surveys

The first step towards active participation from both the patient and the provider was to fill out a short survey regarding their background (Appendix D). Once the survey was completed, a short section could be filled out on the bottom if they would like to participate in an interview (provider), or test (patient).

The collection of demographic information from participants is crucial to this study because it helps place the participants in the context of the information collected in relation to their health literacy rates. Age, ethnicity, gender, and income all relate to the level of education a person can obtain, or what types of medical treatment they can afford. Income can also help explain why some people are unable to follow their dietary instructions since they cannot afford to eat healthily. Because this is an anthropological study, ethnicity must be included because there could be social inequalities that would be overlooked if this information was not collected. It is equally essential to gather this information from the providers because their perceptions could be influenced by their educational, ethnic, and class status. See **Appendix A** for the survey.

Interviews were crucial to this study because it allowed for a better understanding of the provider's role within the dialysis center. The interviews helped to capture the meaning of providers' perceptions and knowledge in the context of their overall lives (Kiefer 2007: 123). Each interview was based on a guide that consisted of

questions that elicit information about perceptions of patients and dialysis care, how the clinic functions, the administrative hierarchy in the hospital and the perceived health literacy rates of the patients. This interviewing technique gave comparative data of the provider's perceptions of health literacy.

The utilization of an interview guide had its benefits as well. Efficiency occurs through specific, targeted questions which used potentially scarce informant time to elicit the most essential responses (Bishop 1999: 99). This was particularly important in the medical community, for providers operated under strict time constraints. Interview notes and/or audio-recorded interview texts were then transcribed into Word documents and analyzed using a grounded theory approach (Nachmias 1996: 294), where researchers ask a series of open-ended questions and look for common or recurring themes in interview narratives. These themes or key topics were then translated into schema or models that map interviewee's responses and form the foundation for interpretations.

Key questions that were asked during the interview to elicit the provider's EM did not only include questions pertaining to HL. Questions addressing space, efficiency, time constraints, and sense of autonomy were pertinent to understanding a provider's position within the dialysis center, for a change in environment could affect the way a provider interacts with a patient. For example, a small space and limited privacy could alter the way a provider would normally carry a conversation with a patient. Because the dialysis unit was small and chairs were lined close together, it was difficult to have a one-on-one patient interaction without having other patients overhearing. The key was to address their perspectives on structural barriers that could potentially hinder a positive patient-provider interaction. Questions asked included:

- Do you have a sense of autonomy within your position at the dialysis center?
- How would you describe the effectiveness of the communication strategies employed by your co-workers?
- Do you have adequate space within the dialysis center?
- What are some of the daily challenges that you face working within the dialysis center, and how do you overcome them?
- What drew you to working with dialysis patients?

Some questions about HL included:

- Are there enough opportunities to present health information to patients?
- Do you see a correlation between HL and education? Why or why not?
- What is your ideal patient?

Providers are able to elaborate on their experiences, which creates a holistic picture of their multiple challenges that they must address in order to affectively provide care to their patients. The length of the interview varied and depended on the participant's schedule and interest in sharing information. Interviews generally lasted between forty five minutes to an hour and a half. The length of the interview was not indicative of the quality of information received. Some individuals were more concise than others and were able to relay information in a shorter period of time than others.

3.1.3 S-TOFHLA

For the patients, The Test of Functional Health Literacy in Adults (TOFHLA) is an accurate indicator of the reading ability because it measures comprehension, including the ability to read and understand both prose passages and numerical information (Baker et al. 1999:34). The original TOFHLA took 22 minutes to administer, so a shortened version was developed: The Shortened Test of Functional Health Literacy in Adults (S-TOFHLA). The S-TOFHLA is a 36 item reading assessment tool that takes up to 7 minutes to administer (Chew et al. 2004: 589). The S-TOFHLA is strongly correlated with previously validated health literacy instruments (Chew et al. 2004:589). It is a valid measure of patients' ability to read the materials they are likely to encounter in the health care setting (Baker et al. 1999: 38). The S-TOFHLA differs from other literacy instruments in that it is available in both English and Spanish and in several different lengths (Aguirre et al. 2005: 332). This test is used for this study because it is fast, efficient, and a validated tool for health literacy assessment. The patient's health literacy levels are determined through a ranking of

correct responses resulting in inadequate (0-16), marginal (17-22), and adequate (23-36) levels. These scores are analyzed by using simple statistics such as percentiles.

The S-TOFHLA is an important tool that the medical community can use to measure their patients' capabilities of understanding health information. It is particularly useful for this study because of its efficiency. The S-TOFHLA is available in Spanish but has been excluded from this study. Two dialysis patients are bi-lingual, but were excluded because they were too ill.

3.2.1 Samaritan Dialysis Services

Samaritan Dialysis Center is located within the Good Samaritan Hospital, and was selected for its central location within the mid-Willamette Valley. The four nephrologists that work at Good Samaritan Hospital are responsible for over 2,000 patients with varying kidney functioning levels. They commute to Lebanon and Albany, as well as Lincoln City where a new dialysis center has been recently established. Because patients travel from different cities for hemodialysis treatment at the center, a mixture of individuals from different backgrounds are encountered. This creates an ideal setting for research because it is more representative of a dialysis population. For example, if one was to choose a dialysis center within a city where multiple dialysis centers are available, it could be possible that a homogenous group of people from the same socioeconomic status could be encountered. Patients who opt for peritoneal dialysis treatment usually travel from further distances because they only need to come to the clinic once a month for laboratory tests. For this reason it was important to include them in the research as well.

Figure 5. Total Population of Corvallis, Oregon

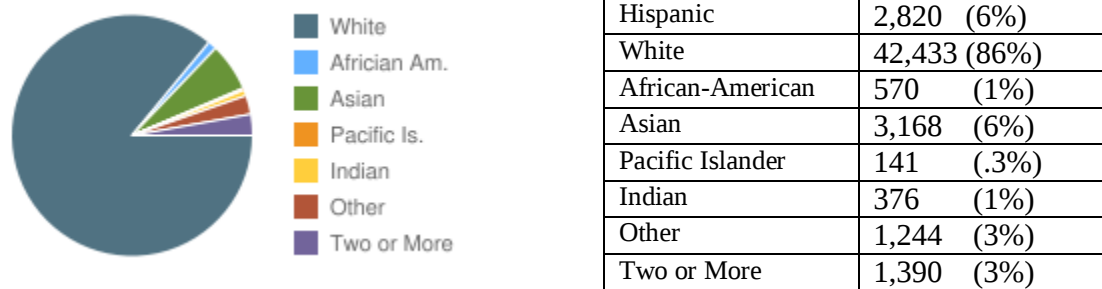


Total Population:	49,322
Median Age:	27
Males:	24,564 (50%)
Female:	24,758 (50%)
Children (0-17)	8,726 (17.7%)
Adults (18-64)	35,626 (72%)
Seniors (65+)	4,970 (10%)

The patient population at the Samaritan Dialysis Center represents an ethnically homogenous group. Ninety eight percent of the surveyed participants described themselves as white. According to the U.S. census bureau, Oregon's population is 83.6% white, compared to the nation average of 72.4% (2011). **Figure 6** provides an ethnic profile in the population of Corvallis. According to the 2000 census, Corvallis has a population of 49,322. The census data for 2000 is used instead of 2010 because socio-economic status is currently unavailable for the 2010 census. The population has since increased by 6,000. The population averages the age of 27 and is 86% white (**Figure 5**).

Previous studies have analyzed the health literacy rates among ethnic minority populations suggesting that minority patients are more likely than white patients to face difficulties communicating with their healthcare providers; up to 20 percent of Spanish-speaking Latinos do not seek medical advice due to language barriers (NA 2004). There are structural barriers that minorities face, including educational attainment, language barriers, and limited or no access to medical services (references). According to Kelly et al. (2006), physicians commonly overestimate patients' literacy levels, which occurs more frequently with minority patients, especially with African American patients than with white non-Hispanic patients. This discordance in estimation of a patient's literacy level may also partially explain the observed health care disparities (Kelly 2006). Saha et al. (2003) observed that both satisfaction with and use of health care services were lower for Hispanic and Asian patients than for African-American and white patients. Ethnic differences in the quality of patient-physician interactions helped explain the observed disparities in satisfaction (Saha et al. 2003)

Notwithstanding the relatively homogenous sample considered in the present study, its findings can inform the academic and medical community about the relationship, if any, between health literacy and ESRD care outcomes and can serve as gateway for future studies of ESRD and health literacy.

Figure 6. Ethnicities in Corvallis; 2000 census

According to Cite Health, Samaritan Dialysis is an average sized dialysis clinic with 12 stations and a total of 3 shifts. It offers both in-center dialysis and peritoneal dialysis services. It currently averages 72 hemodialysis patients and 42 peritoneal dialysis patients. Since there is a constant increase in dialysis patients, there is a wait list to get a chair at the dialysis center. On an average shift, there is one nurse that oversees the floor and the technicians. There are usually four to five technicians staffed. A dietitian, social worker, and nurse manager are present as well. There are two nurses that specialize in peritoneal dialysis and hold training sessions in the clinic. A few other nurses are sometimes present and are doing administrative work in their office. Various jobs are delegated and the nurses are responsible for a wide variety of jobs.

Samaritan Dialysis is unique in that it offers pre-renal education (PrEP) to individuals that are high risk for kidney failure. Once a month, nurses, a dietitian and social worker give brief informative lectures which give a general over view of the dialysis process, nutrition, and Medicare related questions. Individuals can pose questions and concerns throughout the process and also have the opportunity to meet patients while they are on dialysis. This allows the individual to not only grasp the gravity of the situation but also puts them at ease because they are not alone in the

process. In an earlier in-depth study, the researcher examined the effectiveness of the PrEP program in terms to patients' health literacy levels (Wolfe 2006) and reported that the program did improve patient knowledge about their illness. As a result, overall health outcomes were better among PrEP graduates than among those who did not participate in the program.

The information presented will be the background for the following chapter, which will reveal common themes shared by the providers and the HL scores of the patients. This will provide a foundation for understanding the relationship between health literacy among End Stage Renal Disease (ESRD) patients and its relevance for communication between patients and providers. A discussion will then explore the themes in lieu of existing scholarship in anthropology and closely related disciplines.

CHAPTER 4: Results and Discussion

She will tell a patient the same thing over and over and over again; and every time you can see that it looks like they are hearing it for the first time. Some people have been doing it for years. It goes in one ear and out the other, because they have heard it so many times. Most patients want to...do what is right for them, but...after a couple of months, they are having problems remembering to do it, and they don't do it all the time. After a couple months of that, they still haven't gotten it down. They will probably be having the same problems a couple years later. If you can't remedy a problem almost immediately, it's like the same people have the same problems forever.

Good Samaritan Hospital Provider

The quote above demonstrates one of the challenges of being a health care provider -- having to repeat the same information consistently while remaining a dedicated, patient provider. The patient may not be grasping the information because they do not have adequate health literacy skills. There are other factors as well that could be preventing a patient from understanding and using the health information. These factors may include socio-economic status, social support, literacy level, language comprehension, culture, etc. In this chapter, I will examine these factors in light of the level of health literacy among patients receiving dialysis care at the Samaritan Dialysis Center. I will also examine how understanding the perceptions and structural barriers faced by providers can further inform the complex patient-provider relationship.

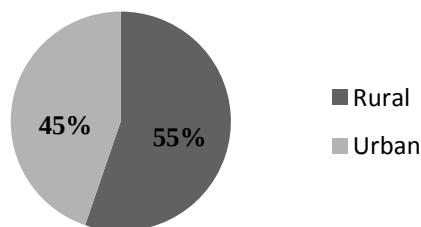
4.1 Patient and Provider Demographics

A component of this study was to measure the HL rates of peritoneal and hemodialysis patients. The collection of demographic information from participants is

crucial to this study because it helps place the participants in the context of the information collected in relation to their health literacy rates. Age, ethnicity, gender, and income all relate to the level of education a person can obtain, or what types of medical treatment they can afford. Income can also help explain why some people are unable to follow their dietary instructions since they cannot afford to eat healthily. Because this is an anthropological study, ethnicity must be included because there could be social inequalities that would be overlooked if this information was not collected. It is equally essential to gather this information from the providers because their perceptions could be influenced from their educational, ethnic, and class status.

The majority of the patients reside in Corvallis, Oregon [n=17]. The other twenty one patients are spread throughout the valley and must commute to the dialysis center. Some of the patients living on the coastal areas are on peritoneal dialysis. They then commute to Corvallis once a month depending on trainings, physician and nurse appointments. **Figure 7** displays the percentage of patients living outside of Corvallis [urban population]. **Figure 8** displays the distribution of patient population across the mid-Willamette Valley in relation to Good Samaritan Dialysis center.

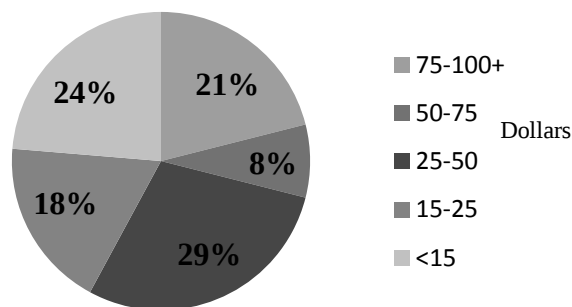
Figure 7. Urban vs. Rural Dialysis Population



The patient population at the Samaritan Dialysis Center represents an ethnically homogenous group. Ninety-eight percent of the surveyed participants described themselves as white. As described in Chapter 3, Oregon's population is 83.6% white, compared to the nation average of 72.4% (2011).

The income of the dialysis patients widely varied. **Figure 9** shows that the majority of the dialysis patient's income fell between twenty five and fifty thousand dollars. Income will be further discussed in the following sections, particularly in **section 4.2.1**.

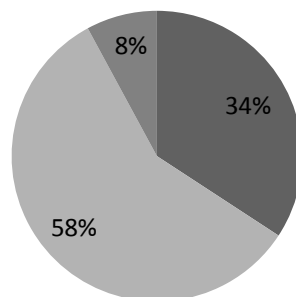
Figure 9. Income



Dialysis patients on Medicare constitute 58% of the patient population. Medicare requires that a secondary insurance pays for leftover costs. **Figure 10** describes the percentage of patients that rely on these services as their primary provider.

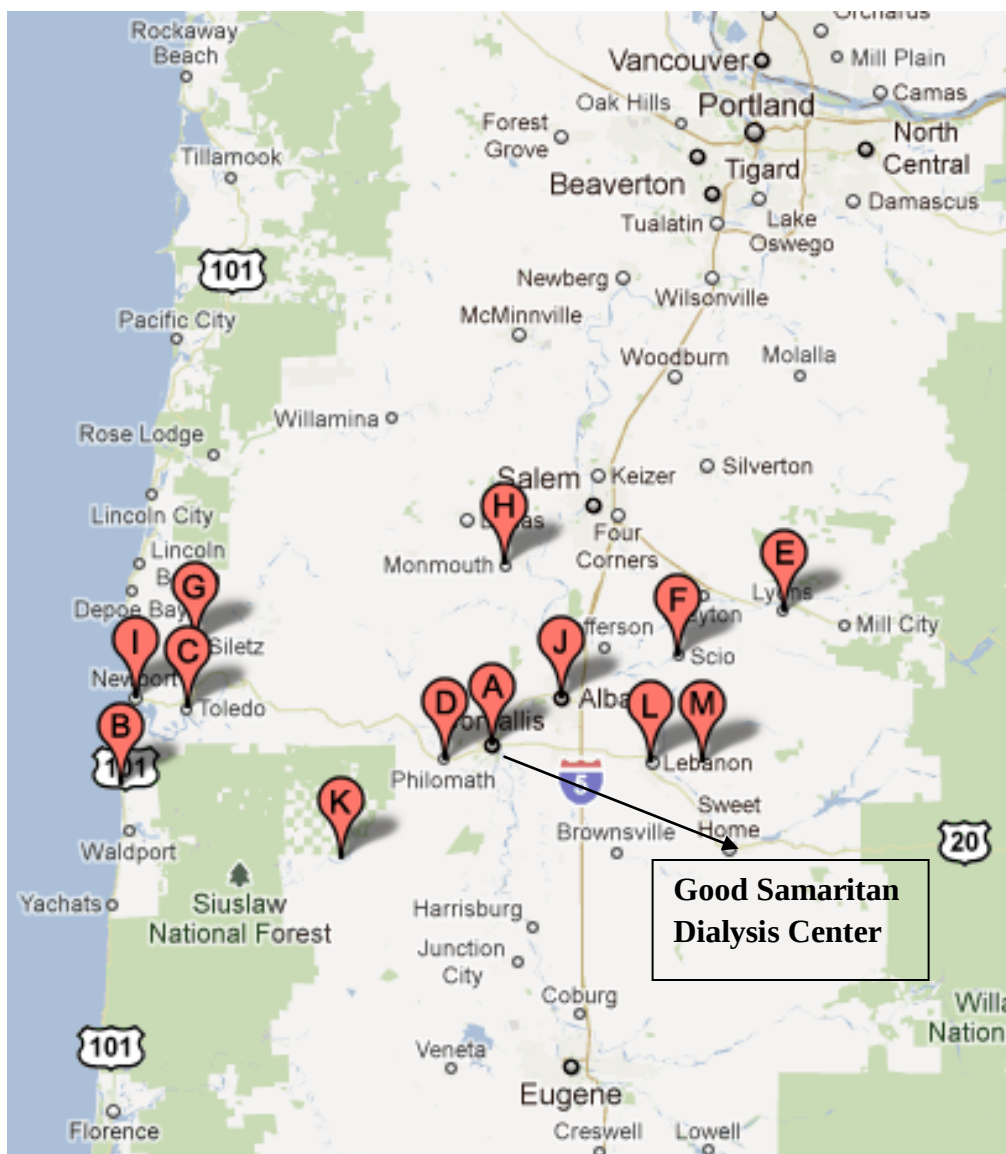
Figure 10. Health Insurance

■ Private ■ Medicare ■ Other



Patients that are on Medicare generally have lower HL skills than patients who are on private insurance. A study by Gazmararian et al. assessed the health literacy among Medicare enrollees in a managed care organization and found that 33.9% of English speaking and 53.9% of Spanish speaking respondents had inadequate or marginal health literacy (Gazmararian et. al 1999).

Figure 8. Distribution of Patient Population throughout the Mid-Valley



4.1.1 Health Literacy Results

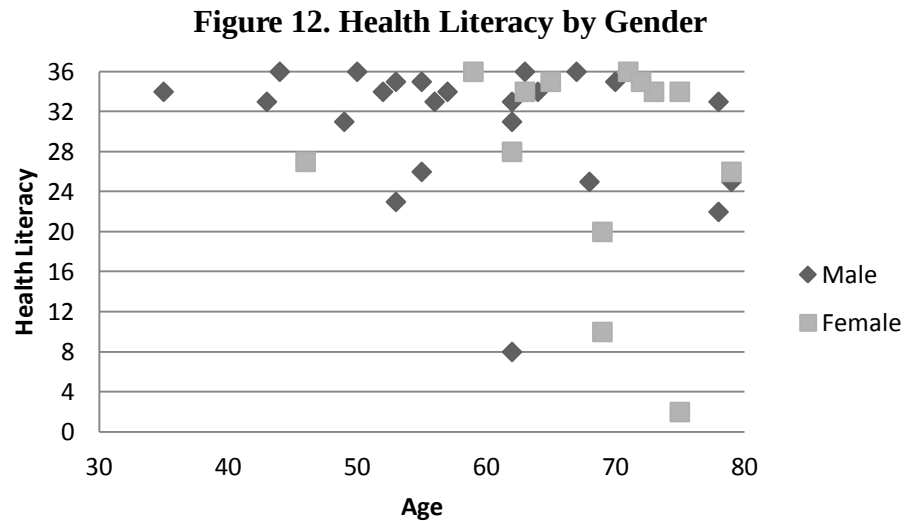
A total of thirty-eight patients took the S-TOFHLA health literacy test. The results indicated that 87% [n=33] of the patients have adequate health literacy and <3% have marginal and inadequate health literacy [n=5]. **Figure 11** breaks the results down according to HL versus education. Surprisingly, individuals with a Bachelors degree scored higher than the ones with a Masters or a PhD [31]. The sample size for individuals with a Masters/PhD was too small to make a direct comparison. **Table 4** goes into greater detail by breaking the averages down. Individual with a high school diploma and associates degree averaged the same score [30]. Although a larger patient population sample is needed, the result for thirty eight patients shows that there is not a direct correlation between HL and education. These findings oppose the perspectives of the providers, which will be discussed in the following sections.

Figure 11. Health Literacy vs. Education



In comparison to gender, males scored higher than females. This could be because more males took the HL test [n=25] than females [n=13]. **Figure 12** compares HL rates to age and gender. An increase of age shows a decrease in HL scores. According to **table 4**, males on average scored a 31 while females scored a 27. A larger sample size is needed in order to see if there is a significant correlation between gender and HL scores. If females do score lower than men on average, it would be

important to find out why because with increased age women could be possibly facing challenges associated with social support.



Literature has associated age with lower HL levels (Gazmararian 2003). For the growing population of older Americans aged 65 years or older—expected to reach more than 71 million by 2030—difficulties with health literacy can complicate already challenging health problems (UAA 2007). This study supports this. According to **table 4**, HL dropped as age increased. For example, patients under the age of fifty tended to score higher [32] compared to patients between the ages of seventy-one and eight-one, which scored an average of 27. **Figure 12** examines HL versus age, in relation to whether or not patients attended the pre-renal education course before starting dialysis. This study, among others (Wolfe 2006) suggests that patients who attend the course have higher HL scores.

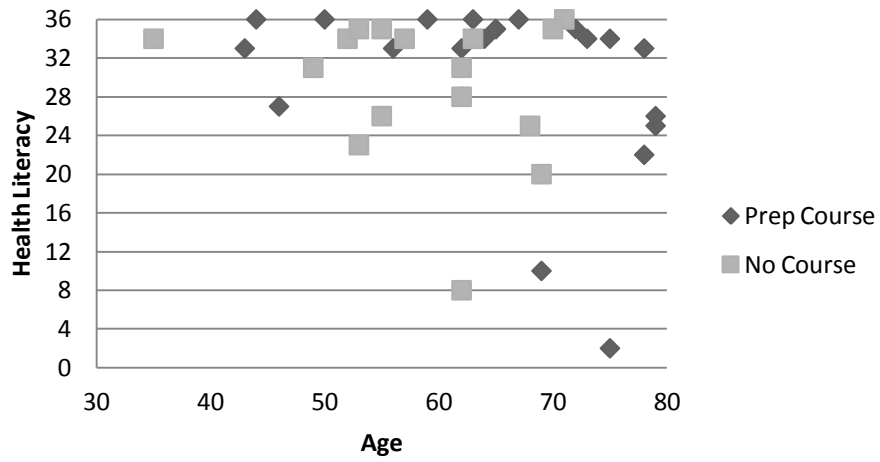
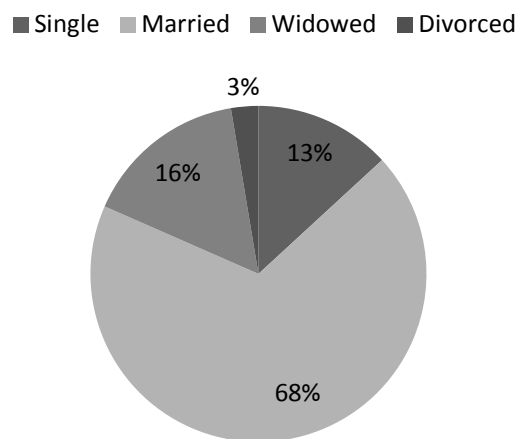
Figure 12. Health Literacy vs. Age

Table 4. Health Literacy Levels in Relation to Demographic Characteristics

Characteristics	Average Health Literacy Level	TOFHLA
Age (Mean)	36	
<50	32	Adequate
51-60	32	Adequate
61-70	28	Adequate
71-80	27	Adequate
Gender		
Male	31	Adequate
Female	27	Adequate
Ethnicity		
Caucasian	29	Adequate
Asian	36	Adequate
Hispanic	33	Adequate
Residence		
Rural	30	Adequate
Urban	30	Adequate
Level of Schooling		
High School	30	Adequate
Associates	30	Adequate
Bachelors	36	Adequate
Masters/PhD	31	Adequate
Marriage Status		
Married	31	Adequate
Divorced	35	Adequate
Widowed	25	Adequate
Never Married	27	Adequate
Kidney Function Level		
Unknown	28	Adequate
ESRD	31	Adequate
Stage 4	20	Marginal
Stage 3	28	Adequate
Stage 2	35	Adequate
Stage 1	35	Adequate

Results from the S-TOFHLA test suggest that marital status may have a correlation with HL scores. The majority of the patients are married. **Figure 13** shows that 68% of patients are married, where as 13% are single, 3% are divorced and 16% are widowed. Single and widowed patients had the lowest average HL scores compared to patients who have been divorced [35] and are married [31] (**See Table 4**). This shows that social support is important in relation to HL skills. Literature suggests that social support helps individuals cope with health problems may alleviate the adverse health consequences of low health literacy (Lee et al. 2009).

Figure 13. Marital Status

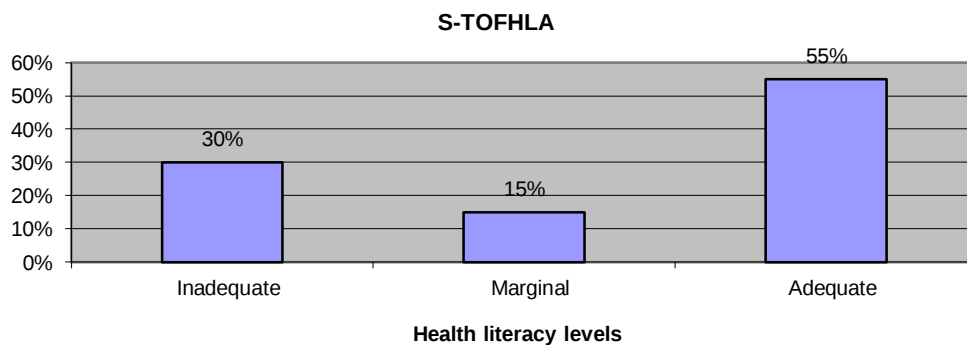


Surprisingly, individuals from rural and urban areas averaged the same health literacy score [30] (**see figure 7**). This contrasts from literature, which reveals that individuals from rural places have lower health literacy skills due to a higher incidence of poverty and lower educational levels compared to urban areas (AHRQ 2004). Forty five percent of the Good Samaritan dialysis population live in rural areas outside of Corvallis. According to this data, location does not have an apparent effect on HL levels. This sharply contrasts with a study that was conducted in the same dialysis unit in 2006. A comparison of health literacy levels and residence demonstrated that those in rural areas were twice as likely to experience low health literacy than those from an

urban residences. Participants that came from urban areas had a 27% inadequate health literacy level compared to 45% of participants in rural areas. Similarly, 64% of those from an urban residence had adequate health literacy and only 33% of those from a rural residency (Wolfe 2006). According to this population, there is a strong correlation between residence location (urban vs. rural) and one's health literacy level.

Wolfe's health literacy study in the Good Samaritan dialysis center revealed that 30% had inadequate health literacy levels, 15% had marginal health literacy levels and 55% had adequate health literacy levels (**Figure 14**).

Figure 14. Health Literacy Levels of Participants from 2006, Wolfe

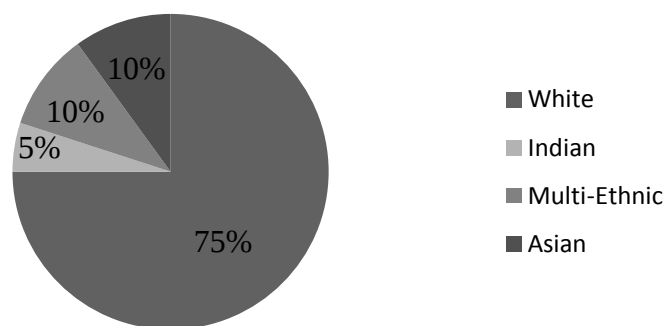


The discrepancy of health literacy levels over a period of five years could be due to her smaller sample size of twenty. Wolfe's recommendations for the PrEP program could have also targeted new dialysis patients which would have improved access to health information and literacy rates. Wolfe's study revealed that participants overwhelmingly felt they acquired more knowledge about ESRD by attending PrEP.

4.1.2 Provider Demographics

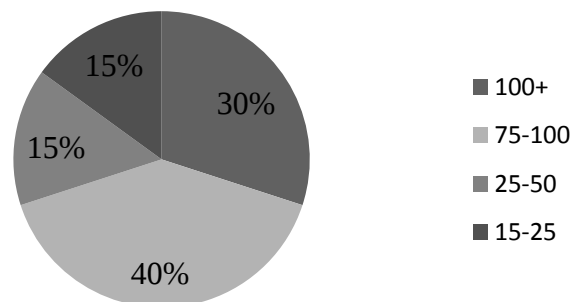
Provider demographics provide a context for their perceptions, which could be influenced by their educational, ethnic, and class status. A total sample of twenty providers participated in this study. The occupations held by the providers are as follows: 2 nephrologists, 1 physician assistant (PA), 1 social worker, 1 dietitian, 2 office workers, 1 nurse manager, 7 nurses, and 5 technicians. **Figure 15** displays the ethnic background of the providers.

Figure 15. Provider Ethnicity

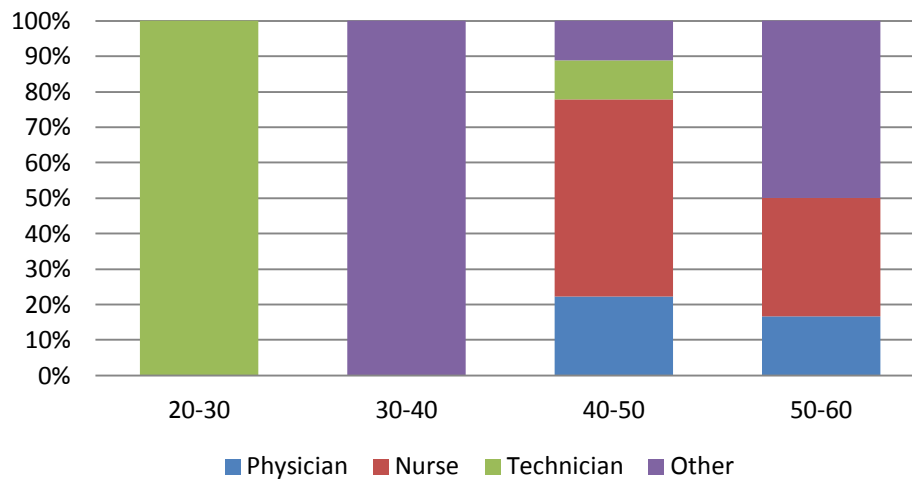


The physicians including the PA are ethnically diverse. The nurses and the technicians were the most homogenous group, where only one provider was from a different ethnic background. The ethnicity of the provider is important because their cultural background can influence their own explanatory model (EM). However, according to Lupton, homogeneity among doctors is promoted by similar training in Western medical schools, which essentially ‘imbue them with a fairly consistent biomedical perspective’ (Lazarus 38: 1986). This is particularly evident in some of the responses of the nephrologists, which will be further discussed in the following sections.

The income of the providers ranged from fifteen to over a hundred thousand dollars each year (**see figure 16**).

Figure 16. Provider Income

Technicians tend to be younger. Their mean age is 29.83 years old, where as the nurses mean age is 48.66. **Figure 17** shows that there is only one technician that is over the age of forty, where as the rest fall under the age bracket of 20-30. The ‘other’ category consisting of the social worker, dietitian, office workers, and nurse administrator had the most diverse age group, ranging from thirty to sixty years of age.

Figure 17. Occupation vs. Age

Providers were mostly satisfied with their occupations. **Figure 18** shows that 65% of providers were very happy with their job, 20% shows that they are somewhat happy, and 15% report that they are neutral.

Figure 18. Job Satisfaction

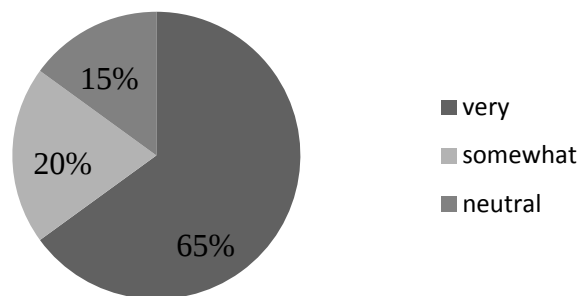
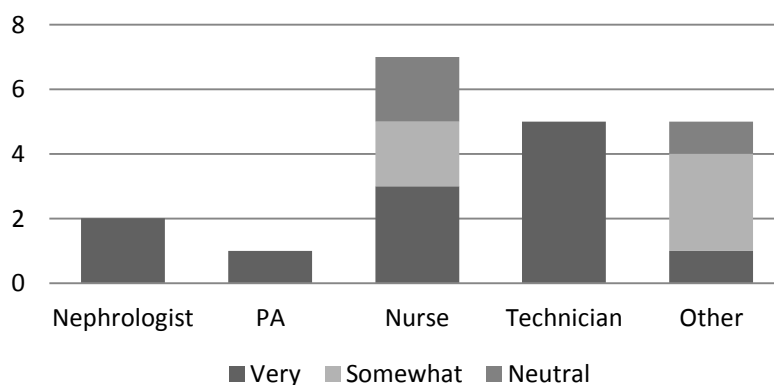


Figure 19 shows that technicians, nephrologists, and the PA are the most satisfied with their jobs, whereas the ‘other’ field (which includes dietitian, administrator, social worker, and office workers) averaged somewhat liking their jobs. This information is important to understand because when compared to the provider’s ethnographies, different opinions regarding their satisfaction vary and do not necessarily match up with the quantitative assessment of satisfaction levels. This will be further discussed in later sections.

Figure 19. Occupation vs. Satisfaction



4.2 ESRD Patient Care: Provider Perspective

Figure 20. Relationship between Patient Care and Provider Perspectives

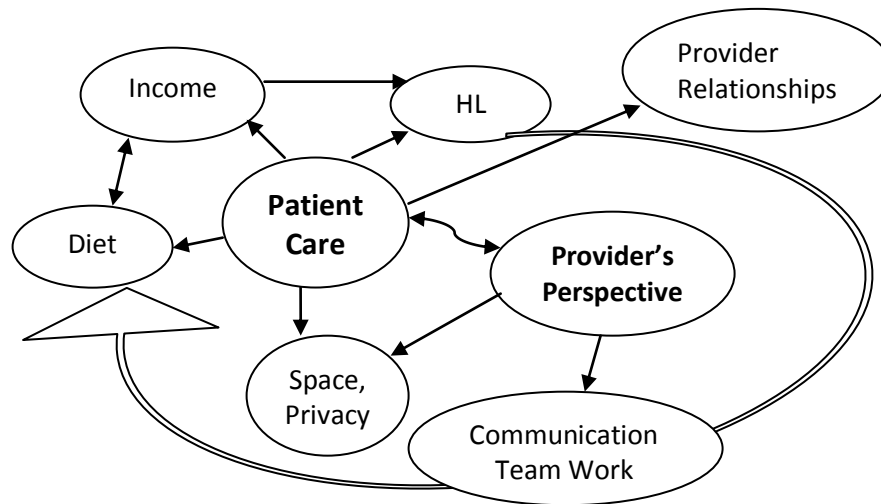


Figure 20 addresses the relationship between patient care and its relation to income, diet, and health literacy. The provider's perspective of patient care and health literacy are shaped by external factors such as space, efficiency, and privacy. Although greatly simplified, the diet will be discussed in tandem with the provider's perceptions. Diet is one of the few aspects that an ESRD patient can control. Several themes emerged in interviews with the providers that concerned the diet. These themes will be discussed in detail in the following sections.

4.2.1 Renal/Diabetic Diet

The renal/diabetic diet is a component of a variety of tasks that patients must be actively aware of. Non-compliance to a particular regimen such as making appointments to see their primary care physician to taking their medication can lead to detrimental health outcomes as well. In the larger picture, the diet may seem like a trivial matter. When describing issues of non-compliance and misguided behavior, the general explanations for this behavior fell under the categories of control, denial, lack of self-interest, or stubborn (their HL is too high). **Table 4** describes other

responsibilities that health care providers wish that their patients would prioritize, but rarely do. While these remain important to consider as well, the diet will be analyzed for it is what the providers discussed the most.

Table 4. Providers List of Duties to Prioritize

-Diet
-Committed to going to dialysis sessions as scheduled
-Take their phosphorous binders with every meal
-Take their medications for other conditions on time
-Lab work (extra's not covered by Medicare)
-Visit nephrologist
-Visit primary care physician

The diet, as mentioned previously, is an important factor in reducing mortality rates in the dialysis population. Nutrients that are considered essential for the normal human body can have a negative effect in the body of an ESRD patient. Dialysis patients must avoid phosphorous, sodium, potassium, and sugar (if diabetic) in food. A variety of pamphlets are available on the topic, including a wealth of recipes that target the renal/diabetic diet. In order to understand what it is like to be a patient facing a sometimes sudden, drastic life style change, I undertook the task of following the diet for a month.

The immediate result of the diet was a complete and utter obsession with what the next meal was going to be. Everything had to be planned out and prepared in advance. It was time consuming and very expensive; a craving for pasta led to spending \$15 to make homemade red bell pepper puree for the tomato sauce replacement. The recipe yielded two cups of sauce. Aside from typical accidents in the kitchen (exploding pyrex in the oven, a broken mixer) a beautiful, salt free pasta dish (at a price of \$16.39) was created. As a student, funds were limited but time wasn't. White cheeses could still be consumed (because it had the least amount of sodium) so a mozzarella and basil pizza was not out of the question. Creativity stretched and

interesting and delicious concoctions were assembled. Would the dialysis community agree?

Patients that are on dialysis are on dialysis for a plethora of reasons. Factors include complications from chronic diseases, traumatic accidents, and life style choices such as diets. One of the most difficult tasks for a health provider is to convince the patient that their current eating habits can no longer remain and that they must eat according to the rules of the diet. According to a nurse, patients “don’t follow... even when we write it out, they don’t follow the diets, they don’t follow their water restrictions... we give them written instructions how to take care of their fistulas and stuff, and a lot of them don’t follow it”. There are varying circumstances which could cause patients to not follow the diet.

The first barrier could be that the diet is not economically viable for most patients. The dialysis population at Good Samaritan Dialysis Center (sample size of 40) is primarily reliant on Medicare (**Figure 10**). Approximately, 47% of the sample patients fell below the national poverty line. The federal poverty line is currently set at \$22,350 for a family of four, and \$10,890 for an individual (ASPE 2011). Twenty-nine percent of the population has a high socio-economic status. In comparison of the two graphs, it can be safe to say that those who earn less depend on Medicare for assistance.

Figure 10. Health Insurance

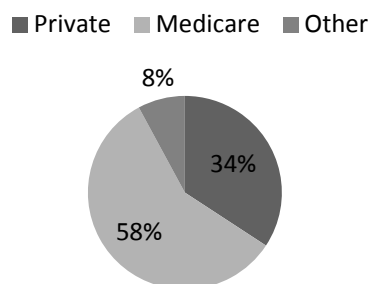
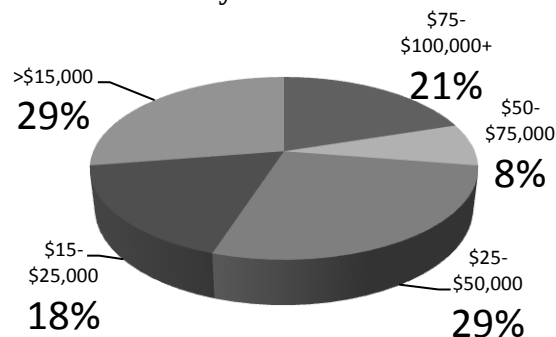


Figure 9. Income Percentage of Dialysis Patients



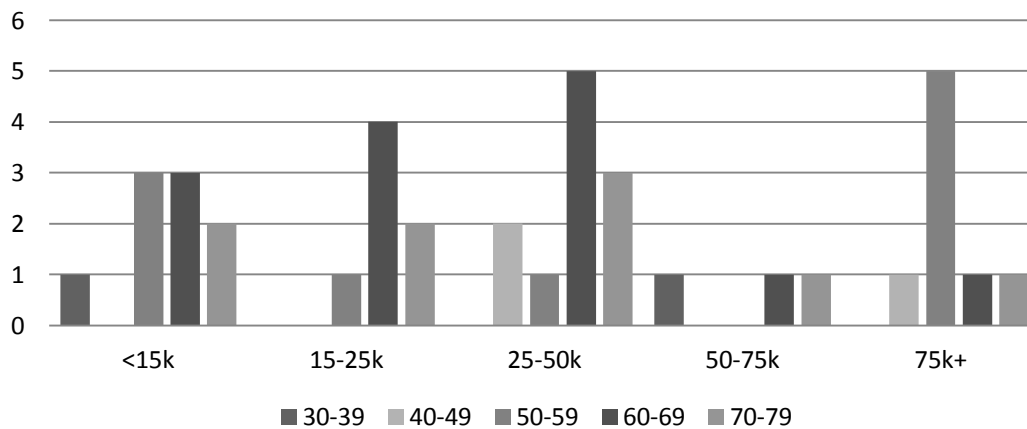
Another circumstance which should be taken into consideration is time and efficiency. Hemodialysis patients are confined to their rigorous routine three days a week. After the session is complete, they are exhausted and weak. Planning a meal takes time and effort, and most patients do not want to spend the rest of their days planning and cooking a meal. A common theme that arose from technicians, nurses, and physicians alike was that non-compliance is directly related to the patient's own self interest. For example, one technician said, "Patients who don't educate themselves and don't see the point, or understand exactly what it is what are doing, don't care." The link between educating and taking responsibility for one's health is the job of a *modern patient*. A nurse on the other hand states, "Some people give up. They are tired of living with a chronic disease and do not want to continue their treatment for various reasons." The nurse acknowledges that there are various factors that contribute to a patient's decision making process.

The diet domain of the treatment plan is less stringent for patients who are on peritoneal dialysis. It is more flexible because they are continually dialyzing, where as hemodialysis patient receives dialysis three times per week. PD patients also have more time to prepare meals, exercise, and are generally in better health. According to the PD nurse, "PD patients...are more satisfied with their health outcomes...and have the luxury to stay at home and take care of themselves, instead of having to come to dialysis". As mentioned previously, PD is paid for by Medicare instantly. However, patients who are on PD are usually the patients that cannot give up their job or work schedule, which could add additional stress in their lives. Patients who opt for HD are not getting their treatment paid for at least three months, and they do not work. It seems that in order to get HD, the individual needs to have the economic means to support themselves.

The individuals or family units who accrue the most income are above the age of 60 (**Figure 21**). Retirement and a comfortable income contribute to more informed

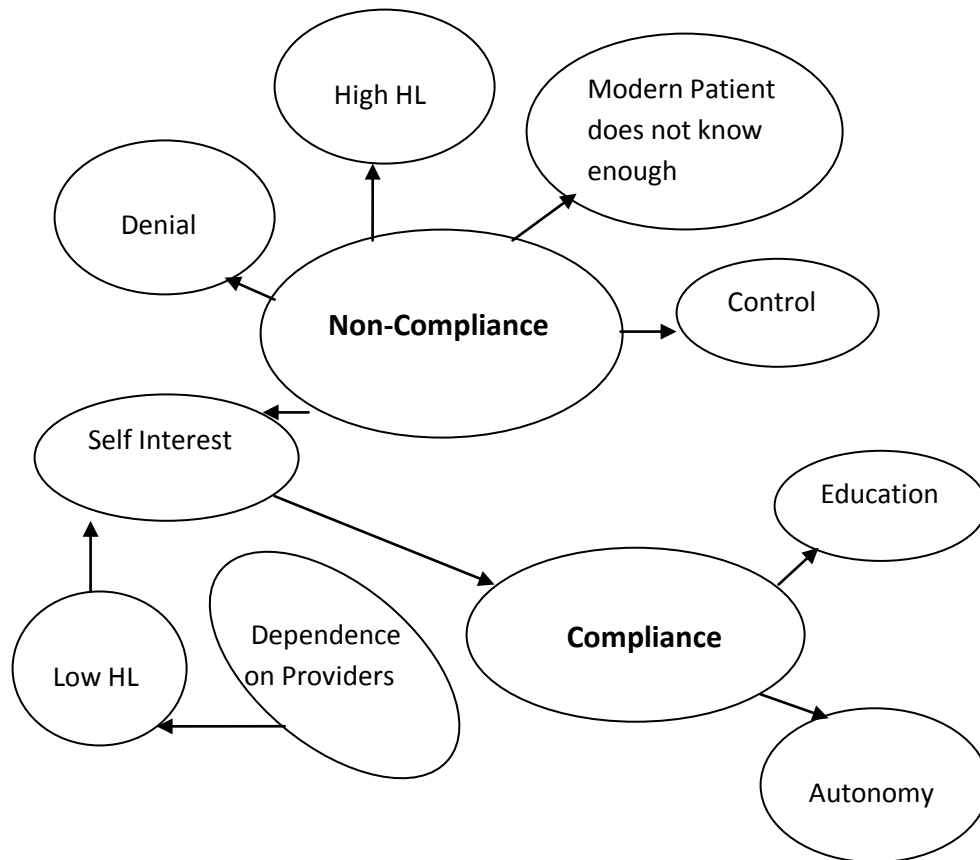
decisions about their health; whereas younger patients have financial responsibilities, stress, and other factors which could possibly contribute to poor choices.

Figure 21. Income vs. Age



Time conflicts and economic considerations aside, health literacy could be a contributing factor to non-adherence to a treatment modality. The quote from the nurse reflects this. “They don’t follow, *even when we write it out*, they don’t follow the diets, they don’t follow their water restrictions... *we give them written instructions how to take care of their fistulas and stuff, and a lot of them don’t follow it.*” Because the sample size of the S-TOFHLA participants did not comprise the entire unit, it is difficult to say that there are patients with inadequate health literacy that have trouble reading and following basic instructions. According to the S-TOFHLA results of the 38 participants, 87% had adequate HL and <3% had marginal and inadequate health literacy skills. Those with marginal skills held either a BA or a PhD. Yet, the providers feel that the majority of the patients in the dialysis unit have inadequate literacy skills due to a persistent lack of compliance on the patient’s part. If health literacy is not a contributing factor to non-compliance, what is? **Figure 22** shows the interaction of themes in relation to non-compliance. Before delving into a series of themes regarding non-compliance and compliance, it is important to understand the provider’s perspective of the correlation between health literacy and education.

Figure 22. Provider Themes Regarding Non-Compliance and Compliance



4.3 The Correlation between Health Literacy and Education

In the largest population survey that has been compiled on health literacy Paasche-Orlow et al. (2004) reviewed 85 health literacy studies that included data on 31,129 subjects. Paasche-Orlow et al. (2004) observed that 26% had inadequate functional health literacy and another 20% had marginal health literacy levels, which suggests that 46% of the population had health literacy levels that were below adequate.

Primary indicators for inadequate health literacy reported are ethnic and cultural minority status, residency in southern and western states in the U.S., formal education level high school degree or GED, age group 65 years or older, physical or mental disabilities, and prisoners, homeless or military recruits (Mika et al. 2005; Williams et al. 1998; Paasche-Orlow et al. 2004). Education and literacy rank as key determinants of health, along with income and income distribution, employment, working conditions and the social environment. However, understanding the complex interrelationship and weighting of these determinants needs further research (Kickbusch 2001).

Samaritan Dialysis Center providers generally agreed that there is a correlation between HL and education. One nephrologist stated,

“I think it has a huge impact on their choices. Obviously their level of understanding will be dependent on their level of literacy. Education and the level of understanding of medical terminology, so on and so forth. I think it’s very important.”

The dialysis technicians agreed on this issue as well. Most suggested that higher education meant more involvement in their treatment and that their outcomes were better. For example, one stated “When patients can advocate for themselves because they are educated, they tend to live longer, they tend to understand exactly what it is that they are doing and why they need to be there.” Other staff including the dietitian, social worker, and office workers were on the fence. “It could. Everyone learns differently” and “It goes both ways.” Although their answers were vague, the nurses had more explanations that supported both theirs and the technician’s perceptions. For example, “patients who are from a lower socioeconomic...they are usually less...not less smart, but they aren’t as educated. They just don’t understand what’s going on.”

According to the providers, education plays an important role in the patient’s ability to have adequate HL. However, there is a point where *too much* understanding is problematic.

4.3.1 *The Difficult Patient*

According to Neuberger, the educated patient is perceived as a ‘new’ challenge for the medical profession (2000). In other words, “over” educated patients tend to question or overanalyze medical treatment and advice (Tomes 2006: 698).

Dieterich (2007) describes patients as increasingly self-aware and critical, partially pretentious or uncomfortable and are sometimes obviously perceived as being a complication during patient-physician interactions.

According to a Samaritan nephrologists, “Positive constructive questions is very important....however it depends on whether they ask us appropriate questions...if they are skeptical of what we do, then obviously this is problematic.”

Overwhelmingly, the dialysis care providers expressed their views on the connection between high HL and non-compliance. These views were particularly strong among the technicians.

Although described in detail in **section 4.6.2**, the technicians surveyed mostly have a high school education. Their knowledge base is different in that they are trained in how to operate the dialysis equipment. There is not a dire need to have knowledge about kidney disease because their job does not necessarily require this knowledge. Although through experience a number of technicians have become knowledgeable to an extent, they may have lesser or an equal understanding of dialysis and kidney disease. Patients who are on dialysis *need* to understand their disease, because they live with it. When a patient is perceived to have too high of a HL skill, this may challenge the technicians knowledge base which creates an uneven power distribution inevitably making the technician uncomfortable. For example, “when a patient is more educated than another, and they understand what is going on, they will push your skills, which is frustrating.”

One technician described a current situation in which a patient was not complying due to their literacy level.

“Right now we have a patient that likes to self-medicate. Although he is an educated man, and he does try to advocate for himself and his own health care he makes poor decisions and we try to explain to him why self-medicating is not appropriate and not okay.”

Similar situations were discussed by the nurses, dietitian and social worker.

“I think some people will have a pretty high HL level, and they think they know what’s best and other people don’t know what’s best for them. They have done their own research, and this is what they believe. You can’t convince them differently.”

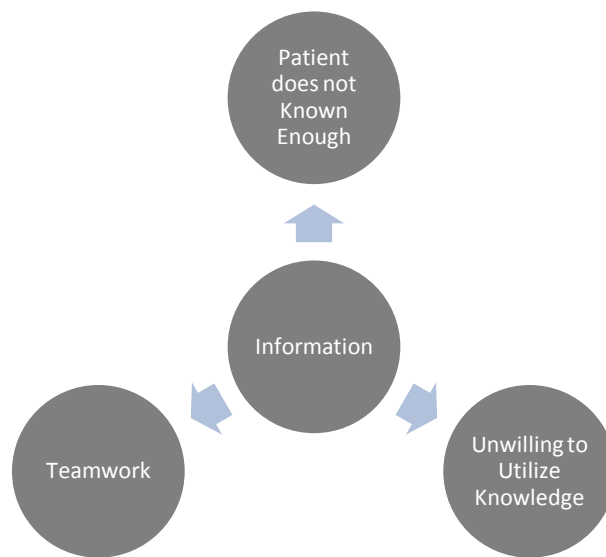
Health literacy in particular and education in general can be seen as either problematic or beneficial concerning adherence to treatment, self-management, and a successful patient-provider relationship. There were only a few providers’ that did not necessarily correlate health literacy with education. While some remained unsure (office staff), some nurses felt that self-interest has a lot more to do with positive health outcomes. For example, one nurse stated, “There was a patient that was not from an educated background, but he caught on really quickly, obviously being literate helps the understanding process, but commons sense plays a large role.” Another nurse made an interesting point. “Health literacy changes as the disease changes.” The accumulation of knowledge is a continuous process, especially if there are complications which could occur from medication, co-morbidities or perhaps even a change in treatment. The information that the providers give the patients provides a platform for the patient’s knowledge base. The following section will describe the process and complications of providing information.

4.4 Information and Teamwork

Webster’s dictionary defines information as “The communication or reception of knowledge and intelligence (Webster 2011).” Information in the dialysis unit can be obtained from any of the health care staff involved during treatment. Technicians,

social workers, dietitians, nurses, and even office staff have daily contact with their patients and share information. **Figure 23** is a simplified version of how the spread of information is impacted by time constraints, teamwork, and the patient's willingness to utilize the information.

Figure 23. Information in Relation to Knowledge Utilization and Teamwork

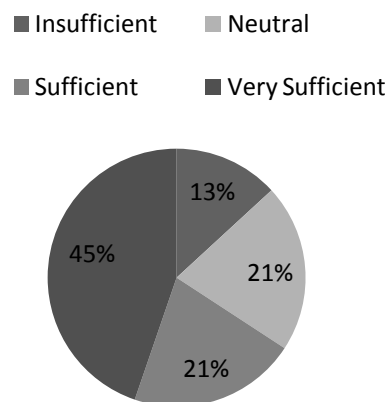


In order to ensure that patients are receiving quality care and are involved in their chronic disease management, communication between providers is essential. When patients ask providers questions it is important that everyone works as a team and relays the same information. According to one nurse, repetition is key for trust and compliance.

“I feel like most of us give the same answer when they ask something, like what medication are you giving? We all tell them the same thing. If we came and told them different things then they would wonder, ‘do they know what they are doing?’ I like hearing the dietitian say something when I just told them the same thing. It’s nice to hear. I listen to what everyone is telling them. We have a good system.”

Another nurse supports this by saying, “If two people are telling the patient the same thing it must be right. Sometimes it’s just as simple as that, having a second opinion.” The collaborative effort of health care workers within the dialysis unit create a positive environment where patients feel free to ask questions regarding their care, and are confident that they are receiving the answers that they are seeking. **Figure 24** describes the percentage of patients that believed that there was a sufficient amount of health information provided. Forty five percent of the patients believe that the sharing of knowledge was very sufficient, where as 13% believed it was insufficient, 21% believed it to be sufficient, and 21% remained neutral.

Figure 24. Health Information Provided



The information that is provided however does not necessarily mean that it is being utilized. One nurse says, “We have so much education we have to do now with the patients, such as providing them with pamphlets. I see a lot of them forget them, throw them in the trash don’t read them. They will do what they will do.” The theme ‘unwilling to utilize knowledge’ became apparent. Providers described at length instances in which information was provided but disregarded.

“They have heard it from everyone: the doctors tell them, we tell them, the techs tell them, the dietitian tells them. We had someone that came in with a

big drink and six kilos over and someone said something about it and she put it down, behind the chair. She knew. She's been told".

Another particularly exasperated provider commented,

"I just spent about thirty minutes the previous month telling him what he needed to do. It just went in one ear and out the other. It wasn't critical for him at that time, it's critical for him now, so he wasn't really paying attention to me enough. I had to go through it all over again. This is his personality, and it's hard to get frustrated with him because that's who they are. You have to work around things."

Repeated interventions are crucial. According to one nurse, a blank face usually equals the need to repeat instructions and that most patients, "won't retain 25% of what they are taught". The dietitian felt that repeated interventions and the chance to get to know people 'create a great chance of making some progress. Sometimes you take two steps forward and three steps back and then a step forward'. Providers attributed the patients' unwillingness to utilize information to them 'not knowing enough'. One nurse reflected on one of her patients,

"There is a patient that cannot manage his sugar levels. His blood sugar is over the 500s. He spends his money on cigarettes rather than on insulin. He knows that he is a ticking time bomb, yet he still does it. We provide samples for medication, and still he won't deal with the problem. He would rather buy his cigarettes. Sometimes I feel like people like him don't know enough to try"

This concept of 'not knowing enough' strengthens the provider's expert status in that it requires the oversight and education of the provider because the patient doesn't know enough to make an independent, rational decision. As the quote above describes, this may be true.

“Something so specialized as dialysis...even I have run across doctors who don’t get dialysis. If you are a doctor that doesn’t always get it, how do you explain it to a lay person?”

According to Dieterich (2007), physicians articulate a caring attitude towards patients and worry that this could be endangered by wrong decisions due to ignorance [on the patient’s part]. For example, a technician stated, “They [patients] do not understand the nuances of dialysis...they haven’t quite put it all together.” Even patients who have a high perceived HL levels, they are at risk of making irrational decisions.

“Many people don’t have a huge background in medicine. They may be highly educated in other areas and know a lot of things about engineering or something like that. But when it comes down to kidney disease, even people in the health care field often don’t know that much about kidney disease.”

The PA has an explanation for the lack of understanding in the health care field. According to her, there is “a ton of awareness of chronic kidney disease...but ESRD, dialysis...no. There was nothing in my education about that. In med school and PA school it was all about disease prevention. When they get to end stage...no way.”

Understanding concepts and information is one thing, but the motivation to apply the concepts to their lives is something else. Self-interest and autonomy are critical factors when it comes to actually utilizing the information. As one provider says, “Some people want you to do everything for them. I consider myself more of a facilitator. I give people the tools so that they can help themselves.”

4.4.1 Autonomy and Self-Interest

“You start out and think, ‘it’s just an education thing’. People just don’t know what they are supposed to be doing. Once they ‘understand’, maybe they know, but maybe they just don’t want to because they don’t care”

-Good Samaritan Nurse

Lack of understanding, perceived low health literacy rates and underutilized information regarding the patients' treatment are problematic. The providers however realize that there is only so much they can do for a patient. A patient must have a sense of autonomy and self-interest in their care in order to comply [to an extent] with treatment. Having adequate HL is correlated with having a sense of autonomy and self-interest.

"It's about how interested they are in caring for themselves. There are some things you can do for people; there are some things that people have to do for themselves. After you have been in the field for awhile you can identify those [patients] pretty quickly"

According to the providers, patients who have higher HL skills are more likely to be self advocates. As previously discussed, having a high HL rate could make the patient difficult, but at the same time the patient cannot be dependent on the provider and must have some say in the treatment. What a patient should and shouldn't do becomes hazy, and largely dependent on who is treating them at that particular time.

The office workers, including the social worker felt that their role in the unit was perceived by patients to be that of a crutch.

"When I started in my twenties, I had a lot more energy and enthusiasm. Life has a way of beating you down. It's almost like a cliché, but it's true you know. You learn short cuts...you learn who you can help and who you can't. You can't really expend the same amount of energy onto everyone. You kind of triage people. I've become a little more cynical."

The office workers and the social worker felt that patients take advantage of their services. One office worker remarked, "the social worker...he is a little more soft hearted and helps them, and sometimes regretfully so, because they want to bring in their plumbing bill too." They see their position in the dialysis unit to provide information and guide, but not to do everything for them. "Our responsibility is to teach them, and then they have to go home and take care of themselves".

Dependence on providers also extends to the treatment process itself.

“A lot of patients...the doctor comes in and says something and they say ‘okay I’ll do it’ because the doctor said so, and they don’t question or understand why they are doing what they are doing.” Another nurse agrees. “They just come in and they say, okay whatever. I am here. Let’s do it. That’s about it.” Although the patients in this case are complying, they are seen as patients that ‘do not care’. Showing some struggle with the provider then shows self interest and advocacy.

Having a lack of autonomy and self-interest extends into non-compliance. The providers in this case feel that there is only so much advice that they can give. One provider states,

“You have to work around it. You know that he is not going to be religious with taking the binders, so I don’t necessarily want to brow beat him. I’m not his mother. I don’t want to bother him every month ‘take your binders take your binders.’”

It is the patients underlying responsibility to do what is recommended. There remain a few more factors that contribute to patient compliance. Control and denial are the last explanations for why a patient is not compliant.

4.4.2 Control and Denial

“If someone says, ‘hey all, phosphorous levels are high, the potassium...but I am going to drink a coke.’ If you know the consequences, I’m not going to beat you over the head for breaking codes. I can’t make you do it. The decision is theirs.”

The above quote demonstrates that the patient exhibits autonomy by disregarding the advice of providers. Disregarding advice does not necessarily mean the patient does not have the adequate literacy skills to comprehend and apply the information to their daily lives. There is a control and denial component that is involved. According to the nephrologist, “Some patients are still in denial. They don’t follow your recommendation because they don’t believe that they are very sick.” The

PA felt that younger patients tended to be more non-compliant than the elderly. “I find that in the younger population, tend to be more non-compliant. They just don’t it, I think there is a denial component to their illness.”

The patient has to retain some control over their lives. Following a treatment plan can completely change a way a patient once lived. The dietitian said,

“There has to be some balance, they have to feel like they are not a patient sometimes. Even if that’s what they can eat and what kind of activities they can do. That’s all they can really do in that situation.”

One of the nurses described the process of patient transformation. At first most are meticulous in following orders and eating the right foods. As time passes, their priorities change and they start to revert back to their ‘old’ habits.

“Strawberries are good you know. But not a whole bowl of them...and then they come in with a big 64oz soda. It’s one of the last things that they have control over.”

During the last few decades, development discourse has taken a neo-liberal turn. Parallel to this, the discourse of social science has become more oriented to matters of individual agency (Dahl 2009). The term ‘agency’ has been conceptualized as a desire for freedom, autonomy and the subversion of social norms. Resistance is seen as relying on a ‘Western humanist expression of free will that is central to the meta-narrative of modernity’ (Mahmood 2005). The definition of agency can carry a range of meanings that may not fit in with this Western perspective. The definition of agency has been extensively debated. According to Keane (2003), much debate in contemporary anthropology turns on the questions of whether human self-determination or autonomy is located in the collective or the individual.

According to Mahmood, agency is not always resistive. There are underlying issues of why the patients aren’t adhering to their treatment. Agency has to be understood in the social and in the institutional environment of the agent (Mahmood 212). This means that the environment in this case is the dialysis clinic, or perhaps their home where they are giving themselves treatment. Other interactions within this

environment could be taking place that could affect the patient negatively, where they are reconsidering their treatment options or life goals. For example, the PA was one of the few providers that pinpointed socio-economic factors as a cause of patients not able to follow recommendations.

“The socio-economic situation is very challenging. Once they understand that ‘okay, I have to take this medication; half the time they can’t afford it. That to me is very, very frustrating. It’s hard enough to them to understand. You need this medication for vitality.”

As previously noted, the patients go through a cycle in their treatment. First they are ready to confront their ‘disease’, but then at the end they become tired and do not want to contend with the constraints. Their act as resistance as seen by the providers is interpreted as ‘non-compliance.’ However, the patient is applying agency in that they are making their own individual choices regarding their treatment. It is their body, not the hospitals. According to Charmaz, social purposes rather than health need to take priority. People delay seeking treatment when they risk losing valued roles, responsibilities, and images of self (Charmaz 282).

A technician supports this by saying,

“If you take their power away, then they feel like there is no use in being an advocate for themselves, so you have to give them the power to make their own decisions. In doing so you have to reeducate them with the proper knowledge so that they can make those decisions.”

Without have the economic resources to apply agency to their lives, it makes caring for themselves if not impossible but more difficult. The dietitian made an extremely valid point,

“There are so many more factors than knowledge and understanding. What about the available resources? So are so many other issues that make it very hard for patients to make changes and to get them healthier, whether they can afford their medication, drive to get their medications, being able to cook on their own...as a dietitian you think, oh, you just have to teach people and they

will do it. There are so many other things that have to happen along the way to help them succeed.”

Income, knowledge and understanding [HL] and the underlying perceptions of the providers [what they can and can't do for the patient] are intrinsically tied. Expectations of the patient encounter are based on a variety of assumptions and idealistic attributes. The latter will be examined in the following section.

4.5 Medical Gaze and the ‘Ideal Patient’

According to French philosopher Michel Foucault, the body is viewed as a series of working parts which can be methodologically separated and treated. When one becomes ill, a part of the body is failing and is diseased. This particular area becomes the focus of the provider's *medical gaze*. The medical gaze is a product of a dominant discourse in scientific medicine that champions the importance of expert medical practitioners using visual cues to assess and monitor patient's bodies (Lupton 54). For example, physicians relied on patients to tell them their symptoms. Now physicians are able to bypass the perceptions of patients and use technology such as x-ray machines to peer inside of the body.

The experience of interacting with medical technologies may lead to a sense of disruption of body image that is distressing (Lupton 56). Both peritoneal and hemodialysis use catheters that transmit bodily fluids such as blood, water, glucose, salts, and other substances. The dialyzing process affects the patient's physical body in that they become bloated. Depending on the types of food consumed, some nurses describe seeing the immediate results of dialysis, “we have had a couple (patients) here where their eyes...they can barely see. Their eyes are so puffy. When they leave you can actually see that the fluid has gone down.” Without the intervention of technological innovation, this would not be possible.

However, physically the patient is altered not only from chemical reactions within their body, but also by being attached to a machine. When hooked up to

medical (and other technologies), the patient's body becomes a cyborg, a juncture of human flesh and machine (Lupton 55). From the fistula that is surgically inserted in the arm, to the artificial kidney; the patient is not just a patient, but a dialysis patient. Their perceptions of themselves as an independent individual are now altered to an individual that is attached to a machine for the rest of their lives. An example of the concept of 'medical gaze' and the transformational process of becoming a cyborg is readily apparent during the pre-renal education class.

During the pre-renal education class (PrEP), future patients are invited to enter the dialysis unit. The purpose of this is to shock the individual into the realization that dialysis is a life altering process. To lessen the blow, future patients hover over and around a patient that is dialyzing and ask questions about the dialysis regimen. What is particularly fascinating about this moment is that the experience of chronic illness means more than feeling physical distress, acknowledging symptoms and needing care. It includes metaphor and meaning, moral judgment and ethical dilemmas, identity questions and reconstruction of self (Charmaz 2007). The individual with the dying kidney is soon going to be the patient hooked to the machine. The process of reconstructing the self take place.

The concept of the medical gaze can be seen here, but in reverse. Citizens are urged to turn the medical gaze upon themselves, and engage in such technologies of the self as monitoring their own bodies and taking preventative action in accordance with medical and public health directives (Lupton 57). To turn down dialysis now would blatantly disregard the expertise and authority of the provider. The potential patient is seen as irrational, ignorant, and unwilling to participate as a *modern patient*.

The providers have put forth a complicated set of expectations for their patient. The patient must be educated, but not too educated to pose a challenge; patients should comply, but at the same time have a sense of autonomy. Patients that are in need of 'control' in their life or are in denial are problematic as well because they are not clearly grasping the idea that they need an intervention. When it all boils down,

patients in the end still don't know enough to make rational decisions concerning their health care. What exactly is their ideal patient?

When asked what their ideal patient was like in terms of self management, all providers immediately agreed that the patient needs to be educated, but not *too* educated. An elusive idea of 'the middle' was something that the provider wanted. According to a nurse self advocacy is crucial. "One who is somewhat compliant, who trusts my experience, and I can trust them that they are going to be upfront with me and say, 'you know, that's too much fluid. Maybe we could get a little more fluid off.'" Self-interest and autonomy then are valued.

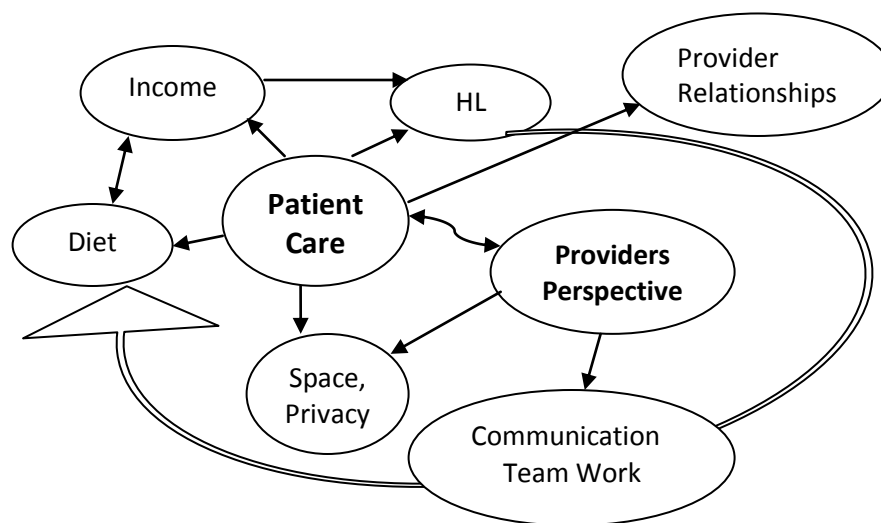
"I would want someone that doesn't necessarily have to be well educated, but someone that can think for themselves. That wasn't to take responsibility for their own health care; that is willing to listen, and be an active participant."

Dieterich (2007) reviewed 73 articles addressing the topic *modern patient* ranging from 1996-2005. Her qualitative research methods examined how the German medical community employed the term *modern patient*. The discourse on the *modern patient* fits into broader modernization processes and is accompanied by new opportunities for patients' empowerment, but at the same time, by new forms of involvement and pressures to accept self-responsibility (284). With the advent of the Internet, research and information is easily accessible. *The modern patient* can also take a part of the role of the doctor, both by co-providing formal health care and by providing educated self-care, for example in chronic disease management (Buetow 2009: 97).

The different opinions and values of the providers reflect that responsibility and rationality are important, but that in the end the provider, although now an active partner, is still in control. Power and knowledge are intertwined. The modern patient is a homogenizing term which expects the patient to be well educated, have a strong socio-economic background, is health literate, and most likely a white, male figure. It does not take into account of the complexities of patient-physician relationships, and the different cultural realities that each possess. The emerging themes from the providers in this study reflect the idea of a *modern patient*.

The focus will now transition to that of the provider's perspective of structural barriers that can potentially impede patient care. The interaction between providers, i.e. teamwork, communication, and their perceptions of space and privacy all greatly influence the type of care that they can provide. **Figure 20** once more shows how these themes relate to one another.

Figure 20. Relationship between Patient Care and Provider Perspectives



4.6 Authoritative Knowledge, Technology and Provider Relationships

An important study conducted by Ellen Lazarus examined the theoretical considerations for the analysis of doctor-patient relationships in a perinatal clinic. Using Kleinman and Singer as comparisons for her work, her findings called for a focus on negotiations between patients' and physicians' health worldviews within the context of their differential power in social relations (Lazarus 54). Patient care and satisfaction with their physician were compromised not because of a misunderstanding of the patient's explanatory model (EM), but because the expectations of the clinical encounter were completely different. Lazarus points out that the clinical setting is not

merely a backdrop for interactions, but it is an integral part of the doctor-patient relationship helping to determine how people act and how much power the physician sustains (Lazarus 49).

In order to understand the provider's perspective of patient care and health literacy, the relationships among providers need to be placed within a context. This particular context is the dialysis unit, which operates differently from most clinics in that patients have direct access to care and knowledge while they are undergoing therapy. Patient care at the Samaritan Dialysis Center is directly overseen by nurses and dialysis technicians. The nurses regularly communicate with the unit doctors to ensure that patient care is properly planned and managed. The relationship among providers is both hierarchical and cooperative. In order to examine this issue further, we must take a brief look at the issue of medical power and authority in the context of a transformative shift in authoritative medical knowledge in the United States in the past two decades.

The US health care system is increasingly characterized by a blurring of provider roles (Sandelowski 11). This blurring of traditional roles has worked towards the advantage of the patient. For example, dialysis patients have access to numerous knowledge sources ranging from technicians to nurses, dietitians, social workers, and nephrologists. Although medical roles are no longer clearly defined, the status of certification as a nurse or a nephrologist still carries the traditional status of authority. In this section, I will argue that the blurring of medical roles has created some confusion, especially between the technicians and the nurses at the Samaritan Dialysis Center.

I will use Robbie Davis Floyd's proposal of authoritative knowledge to analyze the conflicting perceptions based on themes of teamwork and communication between dialysis technicians and nurses. The professional tension between the nurses and the technicians creates an interesting snapshot of some of the structural barriers that they face which is compromising efficiency and communication in relation to patient care.

4.6.1 Nurses

“We are their eyes and ears”

-Good Samaritan Nurse

An influential book written by Margarete Sandelowski investigates how gender and technology have shaped American nursing over the course of time; from the 1870s to the present. In the context of this study, it is important to briefly emphasize the historical role of the nurse and how technology has altered and continues to alter their role as a health care provider. Nurses were handicapped from the onset by appearing to be ‘all-purpose’ female service workers without a defined monopoly of scientific skills. Although the increased use of instruments and implements contributed to the scientific and socioeconomic advancement of medicine, it contributed to functional redundancy of nursing in that no single activity distinguished nursing from other practice above and below nursing in the rigid occupational hierarchy of health care (Sandelowski 60). Nurses are the care takers of the health industry, and they are in a hierarchical position intermediary between the physician and the patient.

Within the historical framework of the medical field, authoritative knowledge plays a central role in maintaining the hierarchies that are in place. Some types of knowledge are discredited and devalued, while others become socially sanctioned, consequential, ‘official’ and are accepted as grounds for legitimate inference and action (Jordan 1992). Both Jordan and Davis-Floyd (YEAR) use the concept of authoritative knowledge to analyze the so called “medicalization” of childbirth in the United States. Medical knowledge supersedes and delegitimizes other potentially relevant sources of knowledge such as the woman's prior experience and the knowledge she has of the state of her body (Jordan 1992). Non-medical knowledge or ‘lay’ knowledge is devalued or delegitimized by all participants, sometimes including the birthing woman herself.

In the context of the dialysis unit, the perceptions of the nurse are important to understand because of the amount of autonomy and authority that they do possess.

Dialysis nurses are expected to fulfill additional expectations that nurses in other medical fields would not require. Dialysis nurse responsibilities vary depending upon educational and work experience. At minimum, nurses perform daily assessments of patients, dispense medication and develop and administer dialysis treatment plans such as fluid therapy according to the physician's orders. At the Good Samaritan Dialysis Center, responsibilities such as patient and provider scheduling, monitoring of dialysis machines and quality care assessments are usually performed by nurses.

In recent years, nurses have felt the need to efficiently manage their time between floor work and managerial work such as creating and implementing policies. Additional paperwork has been problematic because most of the nurses feel that it is pulling them away from their true job: caring for patients. One nurse commented:

“There is a lot of extra stuff I do, especially when we have been short staffed and I have had to work the floor most of the time. It does not give me a lot of time to write those reports. It makes it stressful. I would say paperwork is probably seventy or eighty percent of my job.” Another nurse said, “It's more of the administrative work that I really don't care for. I don't want to do the administrative part. I don't care for that”

Nursing in dialysis can be distinguished from regular floor nursing by the degree of autonomy nurses in dialysis must possess in order to do their job effectively and efficiently. According to a nurse,

“Dialysis is very different from floor nursing. You have to be able to make those decisions and decide what to do without having to go and page the doctor. That's part of it. If you can't work independently, you will not do well in dialysis.” Autonomy and the importance of working independently were themes that appeared in every interview. “It's extreme autonomy. When I was a nurse, you had your roles and you did those roles. Here you need to figure it out; you need to organize throughout your day.”

Nurses however realize that they have autonomy within a boundary. The nephrologists have the ultimate say when it comes to patient care. For example, “We

are not completely autonomous, but we have quite a bit of leeway. Here we have some protocols that we follow, but not that many.” Aside from the technological aspect of working as a nurse, the ‘sentimental qualities’ that a nurse must possess still exists. This includes educating patients about new devices, getting patients to accept and comply with their use and alleviating patient’s fears about them.

Experienced nurses described their changing attitudes about nursing as gaining the ability to sense when a person isn’t feeling well. For example, one nurse states, “You will find that people in the medical profession have a fixed attitude. You can’t make it better for people if you detach yourself. I can sense if someone is upset. My inkling is to go over there and make it better, fix it.”

According to Davis-Floyd (1996), intuition is a form of authoritative knowledge that is largely disregarded and discredited by the western technocratic health care system. Intuition is the result of deep cognitive processes that occur without conscious awareness and cannot be logically explained or reproduced.

Both nurses and technicians value their intuition over their knowledge of technology. Intuitive knowledge reflects experience and competence. One technician says, “I have the ability to look at the person and realize that there is something off, something seems different.” According to Sandelowski (2000), Physicians tend to focus their attention on issues of disease. Nurses however are considerably more open to the inclusion of psycho-social concepts and perspectives (84). While the physician’s reasons of becoming a nephrologist was because of ‘the fascination by pathophysiology and electrolytes’; nurses generally cited having ‘direct care with patients’ and ‘working with a variety of people’ as their decision to become a nurse. Defining nursing as a technology reinforces the idea that nursing is nothing more than manual labor and the mindless application of medical science or orders from physicians (Sandelowski 2000:7). The aspect of care cannot be removed, otherwise nursing, especially in the case of the dialysis center, will be seen as either administrative work or technician work.

4.6.2 Technology

The Samaritan Dialysis Center is a multi-party, multi-task work environment characterized by a single room lined with dialysis machines, chairs, and a central nursing station. The chairs face outward in a slight semi-circle, so nurses and technicians can easily monitor the patients from a distance. The dialysis machine monitors blood pressure, blood flow rate, and body temperature as well as the proper mixture of the dialysate. An alarm sounds when any of these drop or rise. The technicians are trained to hook the patient up to the machine [stick needles into the fistula] and respond accordingly to adjust the controls if an alarm sounds. Generally a technician is responsible for a partial area of the unit. They circulate their designated area while jotting down information on the patient's chart.

The nurses' station houses several computers, telephones and other equipment necessary for operation. The information that is written down on the chart is then transferred to a database. Learning how to use the equipment was a challenge for some.

"The first year I was a tech, I had a hard time because I was reprocessing a dialysis procedure and I always panicked. Did I forget to do something, or was something wrong with the dialyzer? What's going to happen to the patient?"

As technicians learn how to navigate around machines and procedures, their Attention is primarily on the task at hand. Challenges associated with the is 'learning how to stick people' and 'learning how to set up the machine.' Nurses and the technicians have a similar orientation to the work that is to be accomplished. There is no single technology that is restricted to a particular person. Both nurses and technicians manipulate dialyzers; have access to patient charts and the computer database. The nurse explains,

"This is a very technical area. There are a lot of machines, a lot of programming involved and a lot of understanding is necessary concerning how the machine operates. You have to be able to troubleshoot all the dialysis

machines. It's very technical. You need someone that can find that balance between technical and the people part of it.”

Theoretically, the nurses and the technicians have a shared distribution of responsibility and accountability. Because of the blurring of provider roles, more autonomy is placed on the nurse (by the nephrologist) and on the technician (by the nurse). The horizontal distribution of knowledge is problematic in that the status and authority that is held by the title of the provider is still important; there is still a hierarchy in place.

What information goes in and what comes back is a shared concern by all providers, including office workers, the social worker and dietitian. Nurses admit that the majority of the technicians are informed and excel at their jobs. However, there is a power struggle occurring between the technicians and the nurses which is hindering patient care. For example, one nurse says,

“When I work on the floor, you are working with some of the techs. Some of the techs take it upon themselves to do things [which they are experienced and they may doing the right things] but sometimes they do not understand everything that's going on.”

Another nurse states,

“Some of the more experienced techs...sometimes they don't know what's going with the whole story. It may have not been the correct choice, or maybe it's something I should have told the physician but they didn't write it on the flow sheet. I'm not necessarily told at the time.”

Withholding information from the nurse is especially problematic in that the nurses are operating under the nephrologists' license. If the technicians are making decisions based on the patients care without the nurse's knowledge or not sharing pertinent information, patient care could be jeopardized.

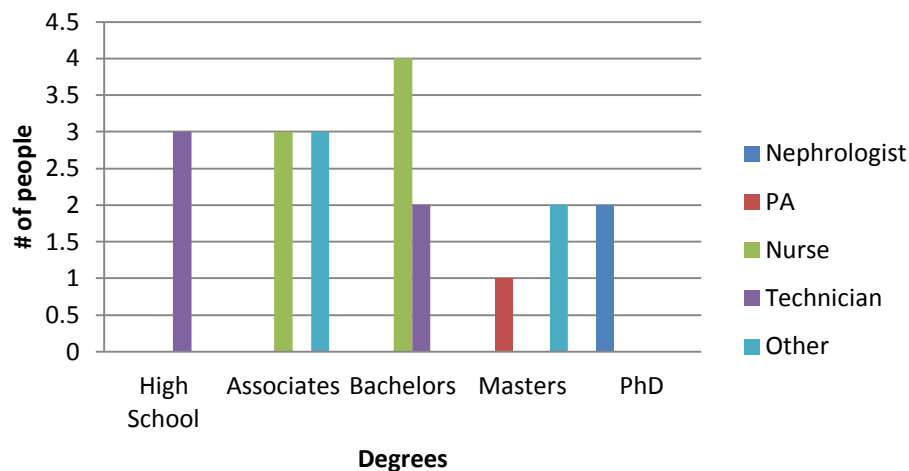
Technicians do not have the overall knowledge base similar to that of the nurses. Most techniques entering dialysis have worked before as Certified Nursing Assistant or CNA (**see figure 25**) Out of the five technicians interviewed, two have a

Bachelors degree and the other three have high school diplomas. Only two technicians had some knowledge of what dialysis and kidney failure entailed [had BA degree].

One technician that didn't states,

"I knew that you go on dialysis when you have kidney disease, but I didn't know the causes of kidney disease. I definitely came in blinded. I didn't even know if it was your liver or kidney that was failing. Which organ is it? I knew it was one of the two, but liver or kidney?"

Figure 25. Job Title vs. Education



The mean age of a dialysis technician at the Samaritan Dialysis Center is 29.83 years, whereas that of the nurse is 48.66 years. Age is an important factor to consider. Technicians feel belittled because they look young and like they do not have the knowledge base that a more seasoned health care professional could provide. The most experience is usually then correlated with knowledge and expertise.

The reasons for choosing to work with dialysis patients vary significantly. Technicians are more interested in the monetary aspect, whereas nurses describe their interest in medicine to be the number one reason for wanting to become a nurse. A quote from one of the newer technicians shows that knowing how to perform the job is more important than actually understanding kidney disease.

“There are probably some things I could research, but I don’t think it’s needed. I think I was taught most of what I needed to know in my training. I mean, I am not obsessed about learning about kidney disease; it’s not something that I’m really passionate about. Just to be able to perform my job I think is all that’s necessary”

Technicians feel like they are not valued or respected by either the providers or the patients. According to a technician who has been working with dialysis patients for a decade,

“Because I am not a licensed RN, I feel like they (nurse) do not particularly listen. They just feel like they know everything. That’s frustrating, especially when I know that some of them have been nurses for a long time, but they are just entering dialysis”.

Because nurses have a higher professional status than that of technicians, they tend to have more decision make power and authority regarding patient care. According to a technician,

“Being a dialysis technician isn’t easy. A lot of technicians are not given enough credit for what we do...by nurses, managers, dietitians, social workers, and doctors. Just about anyone...we do a lot of grunt work. We do a lot of physical labor and it’s tiring. We see the one-on-one side of patient care, or what a doctor lacks, or what the nurses is lacking and how that is affecting the patient... *I think that doctors primarily neglect the fact that the techs are the ones that know the patients the best. They come in and they ask the nurses all these questions and then the nurses come and ask the techs all these questions. It seems kind of like we are the peon and we can’t even be talked to.* Why is it always necessary to have the middle man? It belittles us.”

The above quote reflects the general sentiments that technicians have towards their job and their status. The nurse acts as the intermediary between the patient and the provider. The technician’s role largely depends on making sure the machines are working properly while the nurse does the initial patient assessment before and after

treatment. Because the technicians feel as if they are doing most of the monitoring, the nephrologist should be able to get their information from the technician. This is not the case. For example, “I don’t really know them, I don’t even know some of their names” and “I don’t really get to work with them. I see the PA a lot. Other than that I don’t see them too often to interact with them.”

The lack of interaction between the technicians and the nephrologist could depend on several factors, including time constraints, scheduling, and priorities. It also coincides with authoritative knowledge. Although in some cases knowledge is ‘horizontally distributed’, the technicians do not have the credentials which support their ‘lay knowledge’ that they acquired through working in the field. While some of the technicians are very experienced, the nephrologist will refer to the nurse because they are the ones that are in charge. The power of authoritative knowledge is not that it is correct but that it counts (Jordan 1992:4). Some nurses may have less experience than the technicians, but they carry the certification.

The nephrologists’ role within the dialysis center is seen as inefficient by the technicians. Most described their role within the unit as ‘plagued with miscommunication and confusion’. For example, one technician states,

“Sometimes they don’t talk amongst themselves. One will come in and write an order, a next one will come in and try to write the same order. If the doctor already did, they will change a med that the doctor just changed. It creates confusion.”

Nephrologists are assigned rotations each week, so the patient may see their nephrologist maybe once a month within the dialysis unit. The technicians view the inconsistency of nephrologists within the unit as inefficient. For example, “They ask repetitive questions which make the patients feel like whatever may be happening is not being taken care of properly.”

The nurses feel confident that the nephrologists are appearing at the dialysis unit often enough, which is contrary to what the other health care providers feel. The nurses support their opinion by citing efficiency and time management. For example,

one nurse states “We call them up if we need them. Their time is valuable as well. When they are here, we aren’t able to work with the patient a lot of times. They aren’t really needed.” According to the nurses, nephrologists are under considerable time constraints. “It’s hard for them... a lot of people and units. The coast, Lebanon, Albany...I understand that as well, and I encourage the patients to go and make an appointment in the office if they feel like they need to touch base with them.”

There is also a general agreement that the nephrologists have a relationship with the patient that extends outside of the dialysis unit. “Physicians usually have relationships with the patient from five to ten years. They have a huge understanding. Once they get into dialysis however, the physician sees the patients maybe once a week.” This may not seem like the patient does not have enough time with the nephrologist, however according to a different nurse it is. “In Oregon yes, in New York, no. Here there aren’t too many dialysis patients. They are good over here.” The PA agrees with the nurses. “They share call between four nephrologists, so basically they are only on call one week a month. The other three weeks are to run patient clinic.”

The nurses all agreed that they had a positive relationship with the nephrologists. One states, “I can tell them or ask them anything. I think they realize my experience so they are willing to listen to me too” and “our nephrologists are very good about listening to us. We have a good rapport with the doctors. We don’t feel like we are shut down. We don’t feel like we are being discounted”. While nurses had a general positive attitude about their relationship with the nephrologists, they also stressed that it was because they had to work for the level of trust and autonomy that they have.

The level of trust and understanding that the nurses and the physician’s mutually share helps to create the blurring of roles which enables the nurses to utilize their autonomy at the fullest extent. They are able to make decisions without direct oversight of the nephrologist while still operating within protocol. For example, one nurse stated,

“Today I had a patient infiltrated twice. I told him to go home and we will have him back tomorrow. I told the doctors but I didn’t make the call right then. I did let the doctors know what was going. They don’t need to be called on every single thing. On the weekends there is one nurse here and three techs. You are it. You have to make those decisions all the time on what’s going on and how to take care of the patient.”

One nurse however, made an important point regarding the extent of autonomy that they possess in actuality. He says, “I never have a problem. I communicate with them and do what the doctor says. I give suggestions. Sometimes they take my suggestion, sometimes they don’t. It’s their license, not mine”. This is an important point to consider, because it shows that nurses still operate within strict guidelines.

The PA and the nurse’s confidence in running the dialysis unit without the oversight of a nephrologist is largely due to their autonomy that they hold. The nephrologists on the other hand feel like they have lost a sense of control.

“I used to spend more time which means that I used to travel more. Now we do have a PA. We have to do frequent and very short rounds for each patient (to qualify for Medicare reimbursement). Since the PA started seeing patients, I have seen my patients much less frequently than I have used to. I have mixed feelings about it. My lifestyle is much better, but I would like to see them more frequently.”

The other nephrologist agrees, “No, probably not. That’s the reason why I bring the patient here in the office for follow up visit. To talk about everything in detail.” An office worker felt strongly that the patients were being somewhat neglected by the nephrologists.

“I don’t think the doctors spend enough time here. I think now that they have the PA, a lot of that falls on her. A lot of patients complain about how they don’t ever see them here anymore. Not that they don’t like the PA, but she is not a doctor. They want to ask the doctor questions sometimes. I’m sure that they pay the same amount, whether it’s her or the doctor”

The PA performs some of the duties that nephrologists do when they stop by the dialysis unit. She is able to ‘free up time’ for the nephrologists so they can focus their time elsewhere. According to the PA, she feels like her role is

“The icing on the cake. The nurses, technicians, the dietitian and social worker keep tight control of all of this. I’m just pretty much a liaison between our nephrologists’ and the dialysis unit. I am there to pick up the other three visits. They are always here for the comprehensive labs. I’m basically fluff. They don’t really need me in my opinion.”

4.6.2.1 Teamwork and Communication

Although working independently is valued, teamwork is still a crucial component for working with dialysis patients. Timely communication amongst dialysis nurses, physicians, technicians and other co-workers is extremely important in maintaining ongoing care for their patients. According to the dietitian, “It’s nice to think that they [nephrologists] don’t have to tell me what to do all the time, but it’s also that you want to be able to share information that’s important to you. It can’t be completely separated.”

Both the nurses and the nephrologists have mutual respect for each other’s job roles. One nephrologist states, “I have tremendous trust and great rapport with individual nurses.” Another says, “They are very friendly, very helpful, and very supportive; both the nurses and the physician’s assistant.” The physician assistant has a similar view.

“Everyone here is nice. We have to work collectively as a team. The reason why we are here is for the patient. We aren’t here for anything else. It’s not about my ego, or about the paycheck, it’s to help that patient.”

Both nephrologists extended the idea of teamwork to primary care physicians. “Primary care physicians should be taking more and more responsibility managing early stages of chronic kidney disease. That’s the only way it can go. We will work as

a team.” While they noted that primary care physicians have improved their awareness of the presence of kidney disease significantly, there is room for improvement. ‘It’s not perfect at this point. We still see patients in the emergency room with advanced kidney failure, without any proper renal care whatsoever.’”

Clearly teamwork cannot exist without strong communication. According to the dialysis health care providers, communication is something that needs to be improved. A technician noted, “Sometimes you feel like you are out of the loop. You don’t get the information that you think you need” and “There are some nurses that are better at communication with the techs than other nurses.”

Communication is not limited to sharing information about a patient. It also encompasses an ongoing discussion with management. “Everything we have asked for has been a no with Samaritan...like an increase in pay, better medical coverage.” As well as, “Communication is a big one...mainly from us to the management area. There are a lot of communication gaps.” There are promises that administrators make but then nothing ever comes out of it.

The social worker noted,

“I have noticed communication issues, but of course that’s true everywhere I have been. But one of the aspects here which differs it hat everyone is on different schedules. You might only see a tech or a nurse once a week. If you are working with someone on something, it makes it difficult. All in all, it works out ok”

As the social worker described, communication is a challenge in other jobs as well. However, if the information is not written down or shared accordingly, errors can occur which leads to jeopardizing the patients health or creating redundancy. Communication is not the only factor that is a challenge to providers.

4.7.1 Challenges: Space and Efficiency

According to Lupton, the transfer of knowledge about one's body and one's self is very much one way. Doctors and other health care workers do not reveal their bodies to patients, and rarely do they reveal their private feelings and thoughts. In a Bourdieuan sense, the patient-provider encounter is essentially masked; society thinks a change has taken place but it really hasn't.

There are strict rules and regulations which govern the ability for a provider to disclose personal information. In the dialysis center, HIPAA policy is strictly enforced. According to the providers that were interviewed, there are meetings that take place which inform the providers what is an appropriate interaction and what is not. This ultimately inhibits the ability for health care workers to transfer such knowledge about one's body and one's self.

Keeping relative discretion and anonymity as a health care provider in a dialysis unit is difficult. Patients are seen every other day and providers are working within close quarters where privacy is compromised. "We are supposed to keep this emotional detachment but if we seem them this much, how can you? It's hard to keep that fine line there. Since HIPAA, we are supposed to have this detachment. People don't go into nursing for detachment." According to some of the office staff, gossip is problematic. "They know [patients] more about what's going on than I do sometimes, because they will ask me about stuff that I haven't seen or heard of. I don't want to."

Gossip and confidentiality are issues that are tied directly to lack of space. For example, the nurses' station is centrally located in the dialysis unit. According to an office worker,

"I think the nurses' station is too small. If there are only one or two people it's alright. But lately if you go back there, there are four or five people there and you can't move. You need to do things. The office is way too small. Our storage isn't adequate for what we need."

Because of the location technicians tend to congregate in front of the nurses' station and can be heard discussing their opinions about other staff and personal experiences which may not be appropriate for a work environment. According to an office worker, technicians should, "be more careful about what they are talking about", and "we get concerned about what the patients are overhearing." Nurses shared similar concerns regarding gossip. "Everyone can hear what everyone is talking about no matter how low your voice is."

Aside from gossip, a lack of space makes it difficult to address a patient in confidentiality. As a nurse describes,

"There is a lot of over-hearing. You really need a big space. If it's a really private conversation, I will try and either nab that patient when there is no one around, or have them [patients] make an appointment to see us. We try. Sometimes it's not possible."

The dietitian, social worker and a PD nurse share one office. According to the social worker, "In my other jobs I generally had an office to myself. At first I didn't like sharing an office, but now I don't like being by myself. I don't mind sharing an office, but this particular office...when everyone is here it's crowded." The social worker likes sharing an office with the dietitian because information is easily accessible and they have a good relationship.

The PA on the other hand has no space in the dialysis unit. She stated, "I don't have any home. I share and evade the office manager's space. This is her office. When I am at the dialysis unit, I usually have to hone in on a spot. You see me at one of the nurse's desk. She probably does not appreciate that at all. But I have nowhere else to go." Besides lack of space, she encounters technological issues with her laptop.

I have a lap top and the damn thing never works. When I take it out they always tell me, yeah it works. No it doesn't. I take it into every dialysis and it doesn't work. So yesterday I was in Lebanon, and here I am, both the social worker and the dietitian are there. So I said oh gosh I am screwed. Usually one of them is absent so I can use the computer. I go out to my car for an hour and

half. Sometimes I am in my car. I need to find a place in the hospital where there is a work center”

Without access to technology or a space to do work, efficiency is compromised and so is quality of work. The nephrologists share tight quarters as well.

“We don’t have a lunch room for the employees. We use an examination room. We don’t have enough space. If all four nephrologists were here and they had clinic...it’s not a pleasant experience, because we don’t have enough room.

The office workers have space issues that are particularly discouraging to accomplishing work. According to one, “Here, there is no confidentiality, there is nothing. There is nowhere to go, to even make those phone calls, because all of the rooms are taken. My office used to be in the back, and then they moved me.” Her position involves making important insurance calls. Social security numbers are used and patient confidentiality is at stake because of her location.

“They are up there. They can be hanging in the window while you are trying to give an insurance company the social or id number. Even shutting the little glass windows doesn’t do it. Everything picks up, the headset picks up everything. People walking by, chatting in the back.”

The medical assistant has similar issues.

“There are an awful lot of people that that feel really comfortable that come into the office...yesterday the guy from the cleaning staff stood in there for a long time. I know he works here, but I was just thinking. There are all kinds of things that he could have been seeing, or if he wanted to.”

Gossip, confidentiality and space issues are creating tension between the patients and providers alike. Patients are aware of the relationships between providers. Gossip is detrimental to efficiency, communication and teamwork, but somehow cannot be avoided because essentially, there is nowhere to go.

A positive aspect of this study is that the unit is comprised of a very dedicated, friendly staff that cares very much about patient care. There is disconnect between their perceptions of their patients’ HL skills. While they assumed that the

patients were not literate, there was not an immediate sense of urgency to remedy the problem. For example, the quote at the beginning of this chapter emphasized endlessly repeating instructions. Repeating instructions may not help, for they may not have the HL skills to address the issue.

Overwhelmingly, the provider's perceptions of what their ideal patient would be like supports the concept of the *modern patient*. Although most providers were aware that a lot of patients do not have the socio-economic status to purchase expensive renal/diabetic related foods, they continued to discuss non-compliance in terms of patients being controlling or in denial.

Space, provider relationships and patient care form a complex web which makes it difficult to disentangle. The problems within the dialysis unit cannot be easily remedied due to the economic principles that govern the way the unit runs. The increasing number of ESRD patients is going to create an additional burden.

CHAPTER 5: CONCLUSION

End Stage Renal Disease (ESRD) is a debilitating chronic condition. Patients with ESRD constitute a major portion of the most expensive patients to manage. With a dramatic increase in the number of patients with Type II diabetes and cardiovascular diseases, the National Kidney Foundation (NKK) estimates that approximately 8 million individuals have kidney disease, and that 5.9 million of these individuals will pay for the health care cost through the Medicare system (Collins et al. 2003). Currently (2004) dialysis costs tax payers \$6 billion a year to maintain, which is approximately 3% of the Medicare budget (Mohanram et al. 2004). Although primary care physicians are becoming increasingly aware of recognizing the symptoms associated with ESRD and referring the patients to nephrologists for specialized care, the general public continues to be less informed about identifying early symptoms and seeking medical consult (Kopyt 2009)

Treatment for ESRD requires effective communication between the provider and patient resulting in adherence with medical advice, follow up treatment, self-directed care and maintaining a strict dietary protocol. Chronic disease patients who have limited health literacy and self-management skills struggle with the burden of coping with the complications associated with comorbidities and their treatment regimen. Other factors such as lack of social support, limited income and lack of resources contribute to an increased risk of poor health outcomes.

Health literacy, ESRD, and patient provider relationships co-exist under an umbrella of economic policies which are dictated by neo-liberal values. According to Singer (2007), “People develop their own individual understandings and responses to illness and to other threats to their well-being; but they do so in a world that is not of their own making (1995; 84).” Patients are increasingly expected to be a *modern patient*; a patient that is an active, rational participant that is a partner to the physician. The emergence of the *modern patient* is a testament to the belief that patients are entitled

to and can exercise control over their health decisions; that is if they have the socio-economic status and the health literacy skills to do so. According to Gazmararian, 90 million people in the United States do not have adequate health literacy skills (2003).

Health literacy in the context of ESRD needs to be studied for several reasons. First, many physicians and their patients remain unaware of the diversity of the characteristics of renal disease in the earlier stages (Kopyt 2006). Individuals are diagnosed at the point where dialysis intervention is necessary for survival, adding to the list of treatment options and management skills that they must understand. Secondly, inadequate HL contributes significantly to widening a chasm between patient comprehension and provider care, which results in negative health outcomes and contributes significantly to rising health care costs. Managing consequences of poor adherence to medication alone are excessive and have been estimated to be greater than \$100 billion yearly (Dunbar-Jacob et al. 2001: 57).

This research examines the different ways in which providers within a dialysis center perceive their patient's health literacy rates in order to develop strategies to improve patient-provider interactions and health outcomes. The study was conducted among dialysis services providers at the Good Samaritan Dialysis Center and dialysis patients receiving care at the Center. Data collection techniques included individual interviews, surveys, and the Short Test of Functional Health Literacy in Adults (S-TOFHLA), which measured the health literacy level of the participants.

The results of the study show that a large majority of the patients have “adequate” health literacy, which contradicts the provider’s perceptions of the patient’s ability to comprehend health information. Provider’s perspectives are shaped by their training and work environment. The study suggests that structural barriers and communication issues impede effective patient-provider interactions.

Study Contributions: Health Literacy

My findings have revealed that health literacy does not have a direct correlation with education. Those with an adequate HL level are high school graduates, whereas patients with inadequate or marginal rates have graduate degrees. Medical knowledge is generally not acquired in school. A patient may be highly knowledgeable about engineering, but this does not mean that they will understand kidney disease. There are a variety of factors which affect the patients' ability to adhere to a treatment regimen. These include socio-economic status, age, culture, transportation, and other pertinent resources that will allow the patient to be successful. Although 87% of the ESRD patients in the dialysis unit are health literate, there were many complaints of non-adherence to their diet and medications. Their non-adherence is characterized by lack of motivation, responsibility, high HL skills, denial, and lack of control.

The provider's perspectives of their patients reflect the neo-liberal ideals of rationality and individual responsibility. Patients cannot be expected to be able to navigate the landmines of the medical system when they do not have adequate health literacy skills or the socio-economic status. The concepts of communication, teamwork, and autonomy are crucial to this study and should be studied at a greater length, particularly between mid-level health care providers. There is a growing trend of hiring mid-levels (physician assistants, nurse practitioners) because they cost less and free up redundant activities that nephrologists no longer have to do.

The 'blurring' roles of the health care workers are advantageous to the patient to an extent; however, it creates tension between providers which revolve around the concept of 'authoritative knowledge'. The perceptions of the providers revealed that certification supersedes that of experience, which reinforces the hierarchical position of health care workers within the unit. Poor communication strategies between nurses and technicians are detrimental to patient care and should be further studied.

Health literacy remains a critical component to the overall understanding of health related information. A positive aspect of the dialysis unit was its incorporation of the pre-renal education program (PrEP), which prepares patients for dialysis and the changes that they will face. This is a starting point for individuals to become informed patients, which allows them to choose treatment modalities and become active participants. The patients' utilization of knowledge gained from PrEP, or any other information that is given is hindered by their socio-economic status. Patients may now understand that they must take their binders and avoid processed food, but that does not mean that they can afford to do so. My experience of following the renal/diabetic diet reveals that a patient must be equipped with money, time, energy, and the ability to cook. Having multiple co-morbidities exacerbates the challenges that patients face when adhering to a series of treatment modalities and dietary restrictions while having to cope with the consequences of ESRD.

This study is important in that it highlights the challenges that patients face, while describing the structural barriers that providers encounter on a daily basis. Expectations, communication, and space issues all directly relate to how a provider is going to manage a patient-provider encounter. The emic approach exhibited by this study promotes a larger understanding of the roles and interactions that providers themselves face within the medical system, which hinders their ability to affectively promote health literacy and patient care.

Anthropology

Anthropology is a widely encompassing discipline that has long contributed to our understanding of the culture of medicine and patient-provider relationships in particular. In an effort to take the anthropological discourse on biomedicine beyond the ivory tower, critical medical anthropologists focus their efforts on examining anthropological approaches or models (e.g. system correcting and system challenging

praxis) that can be applied directly to improve health outcomes for all (PROVIDE REFERENCE – SINGER).

The focus of this study is to examine health literacy level among ESRD patients. By addressing the health literacy levels of patients in tandem to provider perceptions I have created awareness by revealing structural barriers that are hindering care. My project contributes to the discipline of medical anthropology by drawing from the explanatory model (EM) to unlock the provider's perspective. Previous studies have utilized the EM to understand the patient's experiences of health and illness. However, by solely concentrating on eliciting and interpreting patients' EMs, the study is forced away from a critical evaluation of the physician's own role in the interaction. The EM of the provider allows for their perspectives to be framed within the biomedical system in which they function in, where set rules and regulations govern their activities. This in turn allows for a critical medical anthropological approach to analyze the provider within the dialysis center.

This study suggests that health reforms such as the Medicare ‘bundling’ policy affects the type of services that providers can provide. The problems with Medicaid and Medicare are systemic of a broader dysfunction within our health care system. Many Medicaid recipients receive fragmented, discontinuous care, while an unprecedented 45 million Americans—15% of the total population—remain uninsured (Horton 2006). The decreasing numbers in funding compared to the rising costs of dialysis creates a troubling question. Has the social safety net been reduced to a bare minimum in favor of a system that emphasizes personal responsibility? Social scientist David Harvey notes, “As the state withdraws from welfare provision and diminishes its role in areas such as health care, public education, and social services, which were once so fundamental to embedded liberalism, it leaves larger and larger segments of the population exposed to impoverishment (Harvey 2005: 76).” Larger segments of the population exposed to impoverishment have less access to healthcare and to basic needs (food and shelter). The economists who create health reform policies concentrate on the monetary aspect, where models of rationality and patients as

‘consumers’ characterize the logic of imposing cost-sharing through premiums and deductibles.

A study by Horton (2006) revealed that ethnography was able to reveal obstacles to care at the institutional level that were otherwise invisible from a bird’s-eye, or policy, perspective. The impacts of Medicaid reforms passed hidden costs onto the poorest Americans that would have otherwise gone unnoticed (Horton 2006). Although on a much smaller scale, my study has contributed to revealing similar barriers that a small dialysis unit in Corvallis faces. Barriers such as space and communication coupled with the complexities of the health care system, policies, and insurance are all affecting the provider’s ability to care for the increasing ESRD patient population.

My study has shown that End Stage Renal disease is an imperative issue that affects patient care on several levels. Individually, the disease warrants a serious treatment regime that requires health literacy and self-management skills. Institutionally, barriers such as space, communication, and provider perceptions (i.e. the modern patient) create serious pitfalls for a positive patient-provider interaction. Finally, at the institutional level: public policy is making it increasingly difficult for providers to accommodate patients’ dialysis related problems by slashing Medicare reimbursements.

This study was designed with the intention of contributing, designing and implementing effective strategies for communication between providers and chronic disease patients, improving clinical and health outcomes among patients, as well as reducing medical costs. While these objectives were originally seen as attainable, there were too many structural barriers for a study of this magnitude to address. Even more problematic, the dialysis unit is no longer not-for-profit. A private corporation (Fresenius Medical Care) purchased the dialysis center from the Good Samaritan Hospital. The new owner of the dialysis center is initiating a series of changes that will affect patient care.

Lessons Learned

Anthropology generally dissuades the idea of generalizing because of the complexities associated with a particular group and their interactions within an environment. Because societies are not encapsulated, ideas, technology and culture are constantly shaping and reshaping the values of individuals within that society. Regardless of not-for-profit or for-profit, a rural unit versus a unit in a city has different challenges and patient populations. This study is unique to the patient population in Corvallis, Oregon.

The dialysis unit is not an exception, and the purchase of Samaritan Dialysis exemplifies this. A not-for-profit center cannot be compared to a for-profit center because of the differing management strategies concerning corporate values. Although the center still operates in the same building, with the same providers and patients, the dynamics are completely altered because of economics. From a corporation standpoint, dialysis is like a laundry mat. The patients are in to wash their blood and then they are out. Hospitalizations will increase because for-profit dialysis units do not draw courtesy labs or treat minor ailments such as a foot infection. This is now the primary care physicians' responsibility. Depending on the patient's resources, they may or may not see their physician in time. Private dialysis corporations focus on cost containment and skimp on services that not-for-profit units usually provide, such as blankets and water.

While the quality of care that providers within Samaritan dialysis unit strived to provide for the patients was impeded by communication and space issues, these challenges could be compounded by the takeover from Fresenius Medical Care. Also at stake is the satisfaction of the providers. A decrease in salary, flexibility, and less autonomy could mean a high turnover rate for nurses and technicians which would be disastrous for patient care.

In light of the recent changes, the provider's perceptions of health literacy, patient care, and working for a not-for-profit unit may drastically change. My study

has opened up the possibility for future research endeavors within dialysis, particularly at the Good Samaritan Dialysis unit. Future research could focus on the providers that transitioned from Good Samaritan to Fresenius Medical Care, which is currently operating in the same unit. A comparison study utilizing the data of this research project could examine the changing attitudes of the providers within a unit that is now purely economically driven. Perceptions of health literacy and provider autonomy within the unit could drastically alter patient care and provider relationships.

Provider's perceptions of some of their patients were seen as needy and dependent. Services that were once done by health care providers may increasingly be the responsibility of the patient. A corporation that does not provide medical services will require a patient to be responsible, rational, and pro-active, though many patients do not possess these qualities. Horton (2006) calls ethnographers to both interrogate the material effects of recent reforms as well as the ideological premises that make them appear common-sense. For example, the changing Medicare policies that are altering the way providers can care for their patients.

The findings of this study can not only be beneficial to not-for-profit centers, but also to for-profit centers. For-profit units would benefit from having educated patients (such as having a program similar to PrEP) which would help create awareness for the responsibilities that patients with ESRD face. This is a proven cost saving strategy and helps alleviate misconceptions that patients have about ESRD. It is crucial that this study is furthered, for there might not be a social safety net to catch the increasing patients with ESRD, and with the rise of corporate dialysis services it is necessary to develop strategies that will limit negative health outcomes.

References

- Agency for Healthcare Research and Quality (2004). Literacy and Health Outcomes. Retrieved from <http://www.ahrq.gov/clinic/tp/littp.htm>
- Ahmed, J., & Weisberg, L. (2001). Hyperkalemia in Dialysis Patients. *Seminars in Dialysis*, 14(5), 348-356
- Aguirre, A., Ebrahim, N., & Shea, J (2005) Performance of the English and Spanish S-TOFHLA among Publicly Insured Medicaid and Medicare Patients. *Patient Education and Counseling* 56, 332-339
- American Public Health Association (2004). Disparities in Health Literacy 2004. Retrieved from <http://www.medscape.com/viewarticle/472719>
- Bahn, I. & Thadhani, R. (2009). Vascular Calcification and ESRD: A Hard Target. *Clinical Journal of American Society of Nephrology* 4, S102–S105
- Baker, D., Williams, M., & Parker, J.(1999). Development of a Brief Test to Measure Functional Health Literacy. *Patient Education and Counseling*, 38(1), 33-42
- Berkman, N., Davis, T., & McCormack, L. Health Literacy: What is it? *Journal of Health Communication*, 15(9), 9-18
- Brown, E., Johansson, L., Farrington., K, Gallagher, H., Sensky, T., Gordon, F., Silva-Gane, M., Beckett, N., & Hickson, M. (2010). Broadening Options for Long-term Dialysis in the Elderly (BOLDE): Differences in Quality of Life on Peritoneal dialysis Compared to Hemodialysis for Older Patients. *Nephrology Dialysis Transplant*, 25, 3755-3763
- Buckelew, L., Harvey, D., & Mello, J. (2003). Provider Panel Presentations. *Nephrology Nursing Journal*, 30(4), 387-395
- Buetow, S., Jutel, A., & Hoare, K. (2009). Shrinking Social Space in the Doctor-Modern Patient Relationship: A Review of Forces for, and Implications of, Homologisation. *Patient Education and Counseling*, 74, 97-103
- Canaud, B., Locatelli, F., Eckardt, K., Stenvinkel, P., & Wanner, C. (2003). Oxidative Stress in End-Stage Renal Disease: an Emerging Threat to Patient Outcomes. *Nephrology Dialysis Transplantation*, 18(7), 1272-1280

- Charmaz, K. (2000). *Experiencing Chronic Illness*. In the Handbook of Social Studies in Health & Medicine. London: Sage Publications, 277-289.
- Chew, L., Griffin, J., Partin, M., & Noorbaloochi, S. (2008). Validation of Screening Questions for Limited Health Literacy in a Large VA Outpatient Population. *Journal of General Internal Medicine*, 23(5), 1525-1497
- Coburn, D., & Willis, E. (2000). *The Medical Profession: Knowledge, Power, and Autonomy*. In the Handbook of Social Studies in Health & Medicine. London: Sage Publications, 377-389.
- Collins, A., Li, S., Gilbertson, D., Liu, J., Chen, S., & Herzog, C. (2003). Chronic Kidney Disease and Cardiovascular Disease in the Medicare Population. *Kidney International*, 64(87), 24-31
- Corvallis Oregon Dialysis Centers and Clinics. (2011). Cite Health [Data file]. Retrieved from <http://citehealth.com/dilaysiscenters/oregon/cities/corvallis/samaritan-dialysis-corvallis.com>
- Dahl , G (2009). Sociology and Beyond: Agency, Victimization and the Ethics of Writing. *Asian Journal of Social Science*, 37(3), 391-407(17)
- Davis, T., Wolf, M., Bass, P., Thompson, J., Tilson, H., Neuberger, M., & Parker, R. (2006). Literacy and Misunderstanding Prescription Drug Labels. *Annals of Internal Medicine*, 145, 887-894
- Dieterich, A (2007). The Modern Patient- Threat or Promise? Physicians' Perspectives on Patients' Changing Attributes. *Patient Education and Counseling*, 67, 279-285
- Dubay, L., Holahan, J., & Cook, A (2005). The Uninsured and Affordability of Health Insurance Coverage. *Health Affairs*, 26(1), 22-30
- Duval, L (2010). Infection Control 101. *Nephrology Nursing Journal*, 37(5), 485-489
- Feehally, J (2010). Ethnicity and Renal Replacement Therapy. *Blood Purification*, 29, 125-129
- Floyd, R. & Davis, E. (1996). Intuition as Authoritative Knowledge in Midwifery and Homebirth. *Medical Anthropology Quarterly*, 10(2), 237-269

- Gazmararian, J., Baker, D., Williams, M., Parker, R., Scott, T., Green, D., Fehrenbach, N., Ren, & Koplan, J (2003). Health Literacy and Knowledge of Chronic Disease. *Patient Education and Counseling*, 51, 267-275
- Gerth, W., Remuzzi, G., Viberti, G., Hannedouche, T., Castela, A., Shahinfar, S., Carides, G., & Brenner, B. (2002). Losartan Reduces the Burden and Cost of ESRD: Public Health Implication from the RENAAL Study for the European Union. *Kidney International*, 62(82), 68-72
- Hahn, R., & Kleinman, A (1983). Biomedical Practice and Anthropological Theory: Frameworks and Directions. *Annual Reviews Anthropology*, 12, 305-333
- Hamilton, J (2009). The Collaborative Model of Doctor-Patient Consultation---Is it Always Culturally Appropriate? *Medical Teacher*, 31, 163-165
- Harvey, D (2005) A Brief History of Neo-Liberalism. Oxford University Press
- Henry, M (2006). Uncertainty, Responsibility, and the Evolution of the Physician/Patient Relationship. *Journal of Medical Ethics*, 32, 321-323
- Jaeger, J. & Mehta, R. (1999). Assessment of Dry Weight in Hemodialysis. *Journal of American Society of Nephrology*, 10, 392-403
- Jordan (1992). Technology and Social Interaction, Notes on the Achievement of Authoritative Knowledge in Complex Settings.
- Keane, W (2003) Self-interpretation, agency, and the objects of anthropology: Reflections on a genealogy. *Comparative studies in Society and History*, 45 (2): 222-248.
- Kelly, P., & Haidet, P. (2006) Physician Overestimation of Patient Literacy: A Potential Source of Health Care Disparities. *Patient Education and Counseling*, 66(1):119-22.
- Kiefer, B. (2007). Health Care Rationing: The Impossible Conversation. *Rev Med Suisse*, 3(124), 2064
- Kleinman, A., Eisenberg, L., & Good, B(2006). Culture, Illness, and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research. *The Journal of Lifelong Learning in Psychiatry*, 4(1), 140-149
- Kovesdy, C., Shinaberger, C., & Kalantar-Zadeh, K. (2010). Epidemiology of Dietary Nutrient Intake of ESRD. *Seminars in Dialysis*, 23(4), 353-358

- Kopple, J. (1998). Dietary Protein and Energy Requirements in ESRD Patients. *American Journal of Kidney Disease*, 32(4), 97-104
- Kopyt, N (2005). Slowing Progression along the Renal Disease Continuum. *Journal of American Osteopathic Association*, 105(4), 207-215
- Lazarus, E (1988). Theoretical Considerations for the Study of the Doctor-Patient Relationship: Implications of a Perinatal Study. *Medical Anthropology Quarterly*, 43, 34-58
- Lee, D., Chertow, G., & Zenios, S (2010). Reexploring Differences among For-Profit and Nonprofit Dialysis Providers. *Health Services Research*, 45(3), 633-644
- Lee, S. D., Arozullah, A. M., Cho, Y., Crittenden, K., & Vicencio, D. (2009). Health Literacy, Social Support, and Health Status Among Older Adults. *Educational Gerontology*, 35(3), 191-201
- Levine, M. (2008). A Challenge for Nephrologists-Increasing Fistula Maturation Rates, Reducing Fistula Maturation Time, and Decreasing Dialysis Catheter Prevalence in the United States. *Seminars in Dialysis*, 21(3), 2280-284
- Lockridge, R. (2004). The Direction of End-Stage Renal Disease Reimbursement in the United States. *Seminars in Dialysis*, 17(2), 125-130
- Lupton, D. (2002). *The Social Construction of Medicine and the Body*. In the Handbook of Social Studies in Health & Medicine, London: Sage Publications.
- Mahmood, S. (2001). Feminist Theory, Embodiment, and the Docile Agent: Some Reflections on the Egyptian Islamic Revival. *Cultural Anthropology*, 16(2), 202-236.
- Mead, N. Woever, P., & Hahn, M (2002). The Impact of General Practitioners' Patients Centeredness on Patients' Post-Consultation Satisfaction Enablement. *Social Science and Medicine*, 55, 283-299
- Mead, N., & Bower, P (2000). Patient-Centeredness: A Conceptual Framework and Review of the Empirical Literature. *Social Science and Medicine*, 51, 1087-1110

- Mehrotra, R., Marsh, D., Vonesh, E., Peters, V., & Nissenson, A. (2005). Patient Education and Access of ESRD Patients to Renal Replacement Therapies Beyond In-Center Hemodialysis. *Kidney International*, 68, 378-390
- Michie, S., Miles, J. & Weiman (2003). Patient-Centeredness in Chronic Illness: What is it and does it Matter? *Patient Education and Counseling*, 51, 197-206
- Mika VS, Kelly, PJ, Price, MA, Franquiz M, Villarreal, R. (2005). The ABCs of Health Literacy. *Family Community Health*, 28(4), 351-357.
- Mohanram, A., Zhang, Z., Shahinfar, S., Keane, W., Brenner, B., & Toto, R. (2004). Anemia and End-Stage Renal Disease in Patients with Type 2 Diabetes and Nephropathy. *Kidney International*, 66, 1131-1138
- Nachmias, D (2000). *Research Methods in the Social Sciences*. Worth Publishers, Inc; 6th edition.
- Nessim, S., Bargman, J., & Jassal, S. (2010). Relationship between Double-Cuff versus Single-Cuff Peritoneal Dialysis Catheters and Risk of Peritonitis. *Nephrology Dialysis Transplant*, 25, 2310-2314
- Neuberger, J. (2009). The Educated Patient: New Challenges for the Medical Profession. *Journal of Internal Medicine*, 247, 6-10
- Nutbeam, D. (2000). Health Literacy as a Public Health Goal: A Challenge for Contemporary Health Education and Communication Strategies into the 21st Century. *Health Promotion International*, 15(3), 259-267
- Orlow MK, Parker RM, Gazmararian JA, Nielson-Bohlman LT, Rudd RR. The prevalence of limited health literacy. *J Gen Intern Med* 2005; 20:175-184.
- Paasche-Orlow, M., Wolfe, E (2007). The Causal Pathways Linking Health Literacy to Health Outcomes. *American Journal of Health Behaviors*, 31(1) 19-26
- Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielson-Bohlman LT, Rudd RR. (2004). The prevalence of limited health literacy. *Journal of General Internal Medicine* 20, 175-184.

- Peter, W., Khan, S., Ebben, J., Pereira, B., & Collins, A. (2004). Chronic Kidney Disease: The Distribution of Health Care Dollars. *Kidney International*, 66, 313-321
- Reunanen, . & Stenman, S (2005). Incidence of End-Stage Renal Disease in Patients with Type 1 Diabetes. *JAMA*, 294, 1782-1787.
- Rosansky, S., Glasscock, R., & Clark, W. (2011). Early Start of Dialysis, a Critical Review. *Clinical Journal of the American Society of Nephrology*, 6(5), 1222-1228
- Safran, D. Miller., M., & Beckman, H (2005). Organizational Dimensions of Relationship-Centered Care. *Journal of General International Medicine*, 21, S9-15
- Saha, S., Arbelaez, J., & Cooper, L. (2003) Patient–Physician Relationships and Racial Disparities in the Quality of Health Care. *American Journal of Public Health* 93(10) 1713-1719
- Salmon, P., & Hall, G (2003). Patient Empowerment and Control: A Psychological Discourse in the Service of Medicine. *Social Science and Medicine*, 57, 1969-1980
- Sandelowski, M. (2000). *Devices and Desires: Gender, Technology, and American Nursing*. The University of North Carolina Press
- Sarnak, M., & Jaber, B. (2000). Mortality caused by Sepsis in Patients with End Stage Renal Disease Compared with the General Population. *Kidney International* 58, 1758–1764
- Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Grotz, K., Castro, C. & Bindman, A. (2003). Closing the Loop: Physician Communication with Diabetic Patients who have Low Health Literacy. *Arch Internal Medicine*, 163, 83-90
- Singer, M. Beyond the Ivory Tower: Critical Praxis in Medical Anthropology. *Medical Anthropology Quarterly*, 9(1), 80-106
- Stanley, M. Peritoneal Dialysis versus Hemodialysis (2010) *Nephrology*, 15, 24-31
- Taylor, T. (2001). Skin Problems and Kidney Disorders. *RenaLife*, 16(5), 32-39

- Tomes, N. (2007). Patient Empowerment and the Dilemmas of Late-Modern Medicalisation. *Lancet*, 369, 698-700
- United States Department of Health and Human Services (2011). The 2011 HHS Poverty Guide. Retrieved from <http://aspe.hhs.gov/poverty/11poverty.shtml>
- Williams, M., Lacson, E., Teng, M., Ofsthun, N., & Lazarus, JM (2006). Hemodialyzed Type I and Type II Diabetic Patients in the US: Characteristics, Glycemic Control, and Survival. *Kidney International*, 70, 1503-1509
- Williams (1998) Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of Functional Health Literacy to Patients' Knowledge of their Chronic Disease. *Archives of Internal Medicine* 158, 166-72.
- Medical College of Wisconsin: Wisconsin Nephrology. Diet for Renal Patient. Retrieved from <http://www.mcw.edu/Nephrology/ClinicalServices/DietforRenalPatient.htm>
- Wolf, M. (2005). Health Literacy and Functional Health Status among Older Adults. *Archives of Internal Medicine*, 165, 1946-1952
- Wolfe, R. (2006). *Health Literacy among End Stage Renal Disease Patients*. Retrieved from Oregon State University on-line database.

Appendix A: Surveys for Patients and Providers

PATIENT RECRUITMENT

1. What is your current age? ____ years
2. What race/ethnicity do you consider yourself?
 ____ Latino/Hispanic Origin ____ African American ____ White/Caucasian
 ____ Asian American ____ Pacific Islander ____ Mixed Heritage
 ____ Other (please specify) _____
3. What is your gender? ____ Male ____ Female
4. What was your age at diagnosis? ____ years
5. What stage of kidney disease were you diagnosed with?
 ____ Stage 1 ____ Stage 2 ____ Stage 3 ____ Stage 4 ____ Stage 5 ____ Unknown
6. How long (months, years) has it been since your initial diagnosis? ____ months
 ____ years
7. What was your insurance status at time of diagnosis?
 ____ Uninsured ____ Private insurance ____ Oregon Health Plan (OHP)
 ____ Other (please specify) _____
8. What was your annual household income at time of diagnosis?
 ____ less than \$15K/year ____ \$15 - \$25K/year ____ \$25 - \$50K/year
 ____ \$50 - \$75K/year ____ \$75 - \$100K/year ____ \$100K or more/year
9. What was your education level at time of diagnosis?
 ____ less than a high-school degree ____ high-school diploma/G.E.D.
 ____ Associate's degree ____ Bachelor's degree
 ____ Master's degree ____ Doctorate
 ____ Other (please specify) _____
10. What was your marital status at time of diagnosis?
 ____ Single ____ Married ____ Committed relationship
 ____ Divorced/Separated/Widowed ____ Other (please specify)

11. Did you have any children at the time of diagnosis? ____ Yes ____ No

If yes, what were their age(s)? _____

12. Were you provided information on dialysis options? ____ Yes ____ No

If yes, who provided the information?

____ Nephrologist ____ Nurse

____ Other (please specify)

13. If yes, how sufficient do you feel the information was in addressing your concerns?

Very Insufficient	Insufficient	Neutral	Sufficient	Very Sufficient
☐	☐	☐	☐	☐

Recruitment for S-TOFHLA

Thank you very much for your time, input, and consideration.

It is greatly appreciated!

Yes, I would like to participate in the health literacy assessment. The researcher may contact me to set up an interview using the information below:

Name: _____

Phone: _____

E-mail: _____

Best time to contact me is:

Day(s) of the week _____ Time(s) _____

Thank you!

PROVIDER RECRUITMENT

1. What is your current age? Between 20&30 30&40 40&60

2. What race/ethnicity do you consider yourself?

_____ Latino/Hispanic Origin _____ African American _____ White/Caucasian
 _____ Asian American _____ Pacific Islander _____ Mixed Heritage
 _____ Other (please specify) _____

3. What is your gender? ____ Male ____ Female

4. What is your position at the hospital? _____

5. How long have you worked at the dialysis clinic?

6. What is your annual household income?

_____ less than \$15K/year _____ \$15 - \$25K/year _____ \$25 - \$50K/year
 _____ \$50- \$75K/year _____ \$75 - \$100K/year _____ \$100K or more/year

7. What is your education level?

_____ Associate's degree _____ Bachelor's degree
 _____ Master's degree _____ Doctorate
 _____ Other (please specify) _____

8. How satisfied are you with your job?

Very Somewhat Neutral Not Very

☐
☐
☐
☐
☐

Appendix B: S-TOFHLA

The following assessment is the Shortened version of the Test of Functional Health Literacy in Adults (S-TOFHLA) that was created by Joanne R Nurss, Ph.D, Ruth M. parker, M.D., Mark V Williams M.D., and David W. Barker, M.D., M.P.H. Included are the instructions given prior to the testing, the actual test form, individual information sheet, and the scoring key.

Short Test of Functional Literacy in Adults
STOFHLA
READING COMPREHENSION

HAND PATIENT THE READING COMPREHENSION PASSAGES TO BE COMPLETED. FOLD BACK THE PAGE OPPOSITE THE TEXT SO THAT THE PATIENT SEES ONLY THE TEXT.

PREFACE THE READING COMPREHENSION EXERCISE WITH:

“Here are some other medical instructions that you or anybody might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing, a blank line is drawn, and 4 possible words that could go in the blank appear just below it. I want you to figure out which of those 4 words should go in the blank, which word makes the sentence make sense. When you think you know which one it is, circle the letter in front of that word, and go on to the next one. When you finish the page, turn the page and keep going until you finish all the pages.”

STOP AT THE END OF 7 MINUTES

PASSAGE A: X-RAY PREPARATION

PASSAGE B: MEDICAID RIGHTS AND RESPONSIBILITIES

PASSAGE A

Your doctor has sent you to have a _____ X-ray.

- a. stomach
- b. diabetes
- c. stitches
- d. germs

You must have an _____ stomach when you come for _____.

- a. asthma
- b. empty
- c. incest
- d. anemia

- a. is.
- b. am.
- c. if.
- d. it.

The X-ray will _____ from 1 to 3 _____ to do.

- a. take
- b. view
- c. talk
- d. look

- a. beds
- b. brains
- c. hours
- d. diets

THE DAY BEFORE THE X-RAY.

For supper have only a _____ snack of fruit, _____ and jelly,

- a. little
- b. broth
- c. attack
- d. nausea

- a. toes
- b. throat
- c. toast
- d. thigh

with coffee or tea.

After _____, you must not _____ or drink

- a. minute,
- b. midnight,
- c. during,
- d. before,

- a. easy
- b. ate
- c. drank
- d. eat

anything at _____ until after you have _____ the X-ray.

- a. ill
- b. all
- c. each
- d. any

- a. are
- b. has
- c. had
- d. was

THE DAY OF THE X-RAY.

Do not eat _____.

- a. appointment.
- b. walk-in.
- c. breakfast.
- d. clinic.

Do not _____, even _____.

- | | |
|-----------|------------|
| a. drive, | a. heart. |
| b. drink, | b. breath. |
| c. dress, | c. water. |
| d. dose, | d. cancer. |

If you have any _____, call the X-ray _____ at 616-4500.

- | | |
|---------------|---------------|
| a. answers, | a. Department |
| b. exercises, | b. Sprain |
| c. tracts, | c. Pharmacy |
| d. questions, | d. Toothache |

PASSAGE B

I agree to give correct information to _____ if I can receive Medicaid.

- a. hair
- b. salt
- c. see
- d. ache

I _____ to provide the county information to _____ any

- | | |
|----------|--------------|
| a. agree | a. hide |
| b. probe | b. risk |
| c. send | c. discharge |
| d. gain | d. prove |

statements given in this _____ and hereby give permission to

- a. emphysema
- b. application
- c. gallbladder
- d. relationship

the _____ to get such proof. I _____ that for

- | | |
|-----------------|----------------|
| a. inflammation | a. investigate |
| b. religion | b. entertain |
| c. iron | c. understand |
| d. county | d. establish |

Medicaid I must report any _____ in my circumstances

- a. changes
- b. hormones
- c. antacids
- d. charges

within _____ (10) days of becoming _____ of the change.

- a. three
- b. one
- c. five
- d. ten

- a. award
- b. aware
- c. away
- d. await

I understand _____ if I DO NOT like the _____ made on my

- a. thus
- b. this
- c. that
- d. than

- a. marital
- b. occupation
- c. adult
- d. decision

case, I have the _____ to a fair hearing. I can _____ a

- a. bright
- b. left
- c. wrong
- d. right

- a. request
- b. refuse
- c. fail
- d. mend

hearing by writing or _____ the county where I applied.

- a. counting
- b. reading
- c. calling
- d. smelling

If you _____ TANF for any family _____, you will have to

- a. wash
- b. want
- c. cover
- d. tape

- a. member,
- b. history,
- c. weight,
- d. seatbelt,

_____ a different application form. _____, we will use

- a. relax
- b. break
- c. inhale
- d. sign

- a. Since,
- b. Whether,
- c. However,
- d. Because,

the _____ on this form to determine your _____.

- a. lung
- b. date
- c. meal
- d. pelvic

- a. hypoglycemia.
- b. eligibility.
- c. osteoporosis.
- d. schizophrenia.

Short Test of Functional Health Literacy in Adults (STOFHLA)

Joanne R. Nurss, Ph.D., Ruth M. Parker, M.D., Mark V. Williams, M.D., & David W. Baker, M.D., M.P.H.

TOFHLA is a measure of the patient's ability to read and understand health care information, their functional health literacy. TOFHLA Numeracy assesses their understanding of prescription labels, appointment slips, and glucose monitoring. TOFHLA Reading Comprehension assesses their understanding of health care texts such as preparation for a diagnostic procedure and Medicare Rights & Responsibilities.

Date ____/____/____

Name _____ M ____ F

Birthdate ____/____/____ Age ____ SSN or ID# _____

Hospital or Health-care Setting _____

City, State _____

Short Form Administered: ____English ____Spanish

STOFHLA - Score

TOFHLA Total Score:
Reading Comprehension Raw Score (0-36)

--

Functional Health Literacy Level:

0 - 16 -- Inadequate Functional Health Literacy

17 - 22 -- Marginal Functional Health Literacy

23 - 36 -- Adequate Functional Health Literacy

July 1995
© Emory University

Large Print Version, English 14 point font • STOFHLA

STOFHLA: Reading Comprehension Scoring Key

14 Point Font

Passage A	Passage A	Passage A	Passage B	Passage B	Passage B
A1 a	A6 a	A12 c	B17 c	B24 d	B33 d
A2 b	A7 c	A13 b	B18 a	B25 b	B34 c
A3 d	A8 b	A14 c	B19 d	B26 c	B35 b
A4 a	A9 d	A15 d	B20 b	B27 d	B36 b
A5 c	A10 b	A16 a	B21 d	B28 d	
	A11 c		B22 c	B29 a	
			B23 a	B30 c	
				B31 b	
				B32 a	

