AN ABSTRACT OF THE THESIS OF

<u>RoxiAnn Blanche Wolfe</u> for the degree of <u>Master of Arts</u> in <u>Applied Anthropology</u> presented on <u>August 23, 2006</u>.

Title: Health Literacy Among End Stage Renal Disease Patients.

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This research examines the impact of low health literacy among patients with End Stage Renal Disease. The sample included individuals who participated in a health education class (Pre-Renal Education Program) offered at the Samaritan Dialysis Services in Corvallis, Oregon. Data collection techniques included participant observation, individual interviews, evaluation of the Pre-renal Education Program, and S-TOFHLA measuring the health literacy level of the participants. The results show that forty-five percent of participants had limited health literacy. The overall evaluation of PrEP was positive and suggested that despite low health literacy of PrEP participants, the educational program is able to effectively convey relevant information and helps patients make appropriate health decisions. © Copyright by RoxiAnn Blanche Wolfe August 23, 2006 All Rights Reserved Health Literacy Among End Stage Renal Disease Patients by RoxiAnn Blanche Wolfe

A THESIS

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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.

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Health Literacy Among End Stage Renal Disease Patients

CHAPTER 1:

ANTHROPOLOGY OF END STAGE RENAL DISEASE

1.1 Introduction

It is more complicated than I thought. I thought that I could just keep plugging along with my shots, and that they would be enough. I wouldn't have to worry about kidney failure or eating properly if I didn't want to. This made me realize that 'maybe you better take care of yourself if you want to be around for a while'...We owe it to our family to take care of ourselves, so this was the wake up call that I've got to pay my dues now. I owe it to my family. It isn't what I think and it isn't what I feel, it's for my family.

Woman Participant (79 yrs.)

This is a quote from a patient diagnosed with End Stage Renal Disease (ESRD). It demonstrates the essence of what it means to suffer from ESRD. It encapsulates not only the individual, but also the family and social dimension of this chronic illness. According to the Annual Data Report: Atlas of End-Stage Renal Disease, over 100,000 new patients start treatment for ESRD annually in the United States. There are another estimated 7.6 million Americans in the early stages of ESRD (pre-ESRD) waiting to begin treatment (ADR 2005).

I became interested in health literacy among chronic disease patients as a result of my close reading of the Healthy People 2010 Report's recommendations to improve health literacy. I learned that one of the local health facilities, Samaritan Dialysis Services in Corvallis, offers a pre-renal education program to patients diagnosed with ESRD. Upon making further inquiries, I learned that this health education program has never been evaluated for its effectiveness in educating ESRD patients.

The proposed study is an anthropological investigation into the lives of 20 ESRD patients receiving health education and treatment at Samaritan Dialysis Services in Corvallis, Oregon. Although the study reports unique characteristics and situations of individual patients, the focus has been on the emergent common themes depicting the complicated nature of the disease and the impact that it has in patients' lives.

Treatment and management of ESRD requires a comprehensive understanding of the causes and consequences of the disease as well as selfmanagement skills. This is especially important in the light of the fact that 90 million Americans have limited literacy skills (Nielsen-Bohlman et al. 2004). It is unknown how many ESRD patients this affects and the potential complications that are caused by a lack of understanding of a disease that requires so much of a patient. This may explain the frustration and overwhelming feeling that many ESRD patients experience, and why many feel that their prognosis is death.

1.2 Goals

This research project was conducted among twenty patients receiving medical care at Samaritan Dialysis Services (SDS) in Corvallis, Oregon. Before beginning treatment, pre-End Stage Renal Disease patients undergo an education class to inform them of their treatment options. This education course is called Prerenal Education Program (PrEP). It is an intervention designed to educate pre-ESRD patients on their treatment options and prepare them for the future through adjustment and planning. This study reports the findings of my research conducted in 2005-06 among a population in the beginning stages of End Stage Renal Disease.

The first aim of this study is to assess the level of health literacy among pre-ESRD patients at SDS. Determining the prevalence of low health literacy among this specific population is a vital aspect of this study. This is accomplished through

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the use of the health literacy assessment test, S-TOFHLA or the Shortened-Test of Functional Health Literacy in Adults.

Another aim of the study is to document the perception of the participants of the Pre-renal Education Program and how it affects their ability to make health related decisions. The specific experiences of the participants are documented through participant observation and ethnographic research. The study demonstrates that the differences in the experiences of participants are based on their health literacy levels while dealing with a complicated and involved chronic illness, End Stage Renal Disease.

The long-term goal of this study is to provide the PrEP team at SDS information in order to improve this vital program. The recommendations based on this program evaluation will allow the dialysis staff to see the effectiveness of the information offered.

The following sections outline biomedical and anthropological approaches to studying chronic diseases. In particular, I discuss the biomedical profile of ESRD and provide an overview of the debate on health literacy in general and among chronic disease patients in particular. These sections are followed by a detailed account of anthropological approaches to studying health behavior, especially in relation to chronic diseases. This section also describes principles and methods commonly used in medical anthropology and provides a theoretical context for the study.

Chapter 2 provides a detailed account of Pre-renal Education Program (PrEP) currently available to all ESRD patients who access treatment in the mid-Willamette Valley region. Chapter 3 outlines methodology used in the study and also discusses its limitations. Chapter 4 provides a detailed analysis of data collected and discusses the results from the applied anthropological perspective. Chapter 5 concludes this study with specific recommendations to improve the PrEP as an effective health education tool.

1.3 End Stage Renal Disease: Biomedical Background

End Stage Renal Disease (ESRD) is a growing medical and public health problem in the United States that disproportionately affects elderly and minority populations. Currently over 450,000 Americans receive treatment for ESRD, increasing by 100,000 each year (Kopyt 2006). This is a disease that is found predominately among the elderly with the median age of the incident population at 64.8 years (ADR 2005). Since 1992 the overall incident rate has increased 36% in patients 75 years and older, where the overall incident rate among patients 64 years and younger has remained stable. ESRD also continues to disproportionately affect minority groups, specifically African Americans, Hispanics, and Native Americans. Treatment for ESRD patients costs Medicare \$17 billion annually and costs non-Medicare sources another \$8.24 billion, incurring on an average a \$54,006 of treatment costs per patient (ADR 2005).

Typically ESRD occurs when the kidneys no longer fulfill their four major responsibilities: balancing body fluids, balancing body chemicals, removing waste products, and releasing hormones. According to Homer W. Smith, M.D., "Bones can break, muscles can atrophy, glands can loaf, [and] even the brain can go to sleep without immediate danger to survival. But should the kidneys fail, neither bones, muscles, gland nor brain could carry on" (People Like Us Live! 1995: 13).

There are four stages of chronic renal failure, which ultimately result in ESRD. These include *mild renal insufficiency*, *moderate renal insufficiency*, *marked renal insufficiency*, and finally *End Stage Renal Disease* (ESRD). These stages are determined by remaining percentage of kidney functioning levels. It is estimated that there are as many as 7.6 million Americans are in the first three stages of chronic renal failure, which is known as pre-ESRD (Xue et al. 2001). Once kidney function levels have reached 15%, it is recommended that individuals begin treatment in order to control the damage to all bodily systems to reduce the effect of symptoms (Core Curriculum for the Dialysis Technician 2001).

1.3.1 Causes of End Stage Renal Disease

ESRD is typically a secondary disease, meaning it is caused by a primary chronic illness. The following is a list of the most common diseases that can result in kidney failure.

- Type II Diabetes-44.8%
- Hypertension—27.1%
- Glomerulonephritis—8.5%
- Polycystic Kidney Disease— 3.2%

Other less common related causes to ESRD include drug toxicity, interstitial nephritis (allergic reaction to antibiotics), obstruction, lupus, cancer, congenital defects, AIDS or sickle cell (ADR 2005).

The two leading causes of ESRD are type II diabetes and hypertension, both chronic illnesses, which require regular management by the patient. Diabetic kidney disease is the leading cause of ESRD. Proper management of type II diabetes through diet, medication, and exercise is important; however, even those with good long-term control of their type II diabetes can still develop ESRD (Xue et al. 2001).

Hypertension or high blood pressure is the second leading cause of ESRD. A unique aspect to advanced cases of high blood pressure is that no symptoms other than a high level of blood pressure may be present until serious damage to the kidneys, heart, blood vessels, and eyes has already occurred. This situation is further complicated by the fact that type II diabetes and hypertension often cooccur. Non-compliance with medication, poor diet, and a lack of exercise is compounded when coupled with a genetic predisposition (ADR 2005).

1.3.2 Symptoms of End Stage Renal Disease

ESRD symptoms vary greatly depending upon the primary cause(s) of the disease. Some patients may experience all the symptoms at early stages; whereas others may reach 15% kidney function levels and not experience any or only a few symptoms. Typically symptoms include urochrome (yellow-gray appearance to the

skin), edema, increased blood pressure, loss of appetite, nausea, vomiting, itching, restlessness, shortness of breath, fatigue, weakness, and mental changes, including depression. Many times the progression of these symptoms is so slow that the patient does not recognize them until they become very debilitating (Core Curriculum for the Dialysis Technician 2001).

Two common effects of the kidneys failing are anemia (shortage of red blood cells), and renal osteodystrophy (bone disease). Anemia is caused by a lack of erythropoietin which is a hormone produced by the kidneys that signal bone marrow to produce red blood cells. Anemia may cause fatigue, dizziness, shortness of breath, heart problems, difficulty concentrating and other serious, lifethreatening diseases. Renal osteodystrophy can be avoided when proper balance between calcium and phosphorus levels can be maintained. If this balance is not achieved, too much calcium is pulled out of the bones, causing them to become weak (Core Curriculum for the Dialysis Technician 2001).

1.3.3 Treatment Options

ESRD patients have three main choices: dialysis, transplantation, or no treatment (Figure 1).



Figure 1. Treatment Options Available to ESRD Patients

Dialysis takes the place of healthy kidneys, which includes clearing toxins from the body and removing excess fluid. Dialysis entails two options; hemodialysis or peritoneal dialysis. Hemodialysis is predominately done by the dialysis staff at a center and uses a dialysis machine and an artificial kidney or dialyzer to clean the blood. In order to have access to the blood, two needles are placed in an entrance, called a fistula, which is surgically placed in the arm (or other location such as the leg) of the patient. Peritoneal dialysis is achieved by filling the abdomen cavity (peritoneal cavity) with dialysate, a liquid that draws extra fluid and waste products out of the blood. This is done by surgically placing a plastic tube called a catheter into the abdomen to create an access for the dialysate to go into the peritoneal cavity, dwell, and then be removed (Core Curriculum for the Dialysis Technician 2001).

Choosing a treatment option is a difficult decision and should be based on the many advantages and disadvantages depending on the needs in the life of the patient. <u>**Table 1**</u> lists some advantages and disadvantages for hemodialysis and peritoneal dialysis patients.

Hemodialysis				
Advantages	Disadvantages			
 Staff performs treatment for patient 	 Requires travel to center three times a week 			
 Regular contact with other hemodialysis patients and staff 	 Treatment at center lasts 3-4 hours 			
 Three treatments per week 	 Fixed treatment schedule 			
 versus everyday No equipment/supplies in home 	 Requires a fistula or graft to access veins 			
 Security of in-care center 	 Two needles inserted for each 			
Less risk of infection	treatment			
	 Diet and fluid limited/restricted 			
	 Waste build up between treatment 			
	 May be tired after treatment 			
	 Machine required 			
Peritonea	l Dialysis			
Advantages	Disadvantages			
 Patient is very involved in own care 	 The time necessary to perform exchanges (four during day or 			
 More lifestyle flexibility 	machine all night)			
 Less restrictive diet 	Permanent external catheter			
 Once a month/regular clinic visits 	 Some risk of infection Storage space needed for 			
 No needles required for 	supplies			
treatment	 No days off 			
 Better blood pressure control 	 Body image changes 			
 Blood sugar control 	 Some possible weight gain 			
 Less stress on body 				
 In-center training 				
 Comforts of home during dialysis 				
 Greater independence 				

 Table 1. Advantages and Disadvantages of Treatment Options for

 Hemodialysis and Peritoneal Dialysis

(People Like Us! 1995)

Treatment choice is individual, and the advantages for one person may not be the same as for another. Many dialysis patients are elderly and have little opportunity for social encounters. Hemodialysis provides an opportunity to meet and regularly see others in a similar situation. For some, treatment becomes an experience in which to socialize with others. However, some may have a busy schedule, and 12 hours a week in a dialysis center plus travel time may not be the way they would like to spend their time. It is important to note that no treatment option with dialysis is desirable. They all require time, effort and changes in the life of the patient.

Dialysis is not a cure. It is a replacement therapy. It is only through the use of dialysis, diet and medication that one's health can be sustained (Baillod 1995). Once dialysis begins, there are even more requirements placed upon the patient. ESRD presents many variables of complications and varying degrees of treatment. With each aspect of treatment (diet, dialysis, and medication), there are specific signs and symptoms associated with compliance (Core Curriculum for the Dialysis Technician 2001).

1.4 Patient Education

Managing ESRD is a function of a coordinated role played by the physician and the patient through self-management skills and treatment. Due to the complicated nature of ESRD, there is an over abundance of information that needs to be understood by a patient in order to make an appropriate treatment decision and learn self-management skills for a positive treatment experience. An education class to explain the affect and treatment options of ESRD as well as the responsibilities of the patient is necessary. Through the use of education a greater understanding of the disease process and treatment options can take place and will increase the level of compliance for some patients. The role of education for dialysis patients is to inform the patients about the nature of the disease and potential complications. Since dialysis is a life-sustaining treatment, aspects of diet, treatment (dialysis/transplantation), and medication have significant importance in maintaining good health. Educating ESRD patients helps them make appropriate decisions for medical and personal management of their disease (Baillod 1995).

ESRD education programs, such as PrEP (Pre-renal Education Program) provide patients with new information concerning their disease, helps them develop needed skills to maintain a healthy life, promotes independence, alleviates anxiety of the unknown by creating a higher self reported health, and allows patients to make informed decisions concerning their health management (Core Curriculum for the Dialysis Technician 2001).

Education is the first step to gaining ownership in the decisions required with ESRD. ESRD is a life changing disease. It not only alters the life of the individual, but also of their families, friends, and co-workers There are preparations that need to be made well in advance of starting dialysis, and PrEP gives them the knowledge, skills and resources to accomplish them.

There have been many positive outcomes from pre-ESRD patients attending an educational course such as PrEP. A study conducted by Levin et al. (1997) documented three specific outcomes among patients who attended an ESRD educational course in comparison to those who did not. The study found a reduction in the need for urgent dialysis (13% vs. 35%). This is significant because when a patient begins dialysis as an emergency, it is typically due to serious medical problems. Also urgent dialysis prevents the patient from being able to make a treatment choice based on their individual lifestyle. Instead, they begin hemodialysis with a catheter instead of a mature fistula, which increases the risk of infection. Second, ESRD patients who attended the education program had less days in the hospital during the first month of dialysis (6.5 days vs. 13.5 days). Finally the study reported significant improvements in the patient's ability to control their blood pressure, calcium and phosphate levels. Not only did patients experience a more pleasant treatment, these results also led to significant savings for Medicare, private insurance companies, and the patient (Levin et al. 1997). Furthermore, education before treatment also showed an improvement in the patient's satisfaction and the ability to delay the onset of dialysis (Mehrotra et al. 2005).

One of the few studies available on the effectiveness and availability of ESRD education looked at incident patients at 229 dialysis units and found that 36% were unaware of their kidney disease until treatment began, or were not seeing a nephrologist until less than four months before treatment. Forty-eight percent did not have any treatment options presented until after hemodialysis had already begun, and 70% of incident hemodialysis patients reported that peritoneal dialysis was not offered as a treatment option (Ravani et al. 2003). There are no statistics available that document the number of ESRD patients that receive education of their disease in a structured setting such as PrEP. It has been shown that those who have the opportunity to learn more about their disease experience a more positive effect even though few if any of the programs have been evaluated or monitored (Mehrotra et al. 2005). However, there have been no studies documenting the level of understanding that these patients achieve from the educational courses, especially in light of their health literacy levels.

1.5 Health Literacy

1.5.1 History

The interest in health literacy began in the mid 1990's after a realization that the general literacy of the population in the United States were at such low levels, many Americans were unable to use a bus schedule, or calculate the total costs of purchases from an order form. Once it was determined through National Adult Literacy Survey (NALS), a nationally based literacy survey that 90 million adults in the United States had limited literacy skills, a connection to health literacy was born. Determining the exact implications of the prevalence of health literacy has been difficult to calculate, but the goal of the medical community is to overcome negative outcomes of low health literacy (Frisch 2005).

According to Ruth Parker, MD, a practicing internist and researcher at Emory University School of Medicine, "Literacy skills predict an individual's health status more strongly than age, income, employment status, education level, and racial or ethnic group" (Wilson 2003:75). It also points out the importance of not only finding the prevalence of low health literacy skills, but also improving those health literacy skills in a way that will positively impact the health of the United States population (Wilson 2003).

1.5.1.1 Inadequate functional health literacy at two public hospitals

In response to the findings of the National Adult Literacy Survey (NALS), Williams et al. conducted the first published study to assess the ability of patients to perform a wide range of literacy tasks required to function in the health care environment, or functional health literacy (1995). The goal of this first health literacy study was to determine to what extent health literacy levels hinder patients from receiving adequate health care. It assessed patients' abilities to understand and apply medical terminology to their circumstances, not just pronounce it. According to Williams et al. (1995), limited health literacy is a barrier that prevents adequate access to health care. Forty-two percent of patients were unable to understand directions for taking medication on an empty stomach; 26% couldn't understand an appointment slip; and 60% couldn't understand the concepts from a standard consent form. The final results indicated that one third of the Englishspeaking population at two public hospitals could not read or understand basic health-related materials. In the past there have been associations made between socioeconomic status and education level to determine a person's ability to comprehend and understand medical information, but this study suggests that literacy limits related to health care are more widespread, cross socioeconomic boundaries, and form a greater barrier to accessing health care than once believed (Ad hoc 1999; Williams et al. 1995).

One of the most efficient ways of improving health literacy would be to identify the patient populations that have the greatest health care needs and the least ability to understand health information. Appropriate health literacy educational tools should then be developed and implemented with systematic evaluation of their effectiveness.

1.5.1.2 Ad Hoc Committee on Health Literacy

Combining the information gathered from the NALS and the findings from the Williams et al. study, the American Medical Association (AMA) wanted to determine the scope and consequences of poor health literacy within the United States (Nielsen-Bohlman et al. 2004). They determined that the health literacy levels in the United States were worse than the statistics from the NALS findings. As a result the American Medical Association (AMA) instigated the Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs (Neilson-Bohlman et al. 2004; Berkman et al. 2004).

The committee consisted of 12 members selected as experts in the field of health literacy with backgrounds in clinical medicine, medical and health services research, medical education, psychology, adult literacy, nursing, and health education. The Ad hoc committee investigated the matter of health literacy in order to determine the consequences of poor literacy in health care settings, the implications of the problem for practicing physicians, areas of research and the ramifications of poor literacy for the U.S. health care system. The committee was even more concerned to find that health literacy was worse among the elderly and those who reported overall poor health, suggesting that those with the greatest need of health care were the least able to function within the health care system. The consequences of this committee have created an awakening to the healthcare community connecting the barrier of limited health literacy to health outcomes (Ad hoc 1999).

1.5.1.3 Healthy People 2010

Each decade, the Department of Health and Human Services compiles a statement of national health objectives. These objectives are designed to address the most significant, preventable health threats. They are stated in different focus areas and have specific goals associated with them as the prevention agenda for the nation. *Healthy People 2010: Understanding and Improving Health* is the most recent form. It identifies 28 focus areas with two overarching goals. The first goal is to increase life expectancy and improve the quality of life. The second goal is to eliminate health disparities that are found among specific segments of the population (Wurzback 2002). Within these 28 focus areas there has been a new addition for *Healthy People 2010* titled *Health Communication* (HHS 2000).

Health Communication has been added to the national health objectives because of the positive effect communication can have on the health of individuals and overall public health through prevention and health promotion. One way this can be achieved is through the exposure to health information through education (HHS 2000). Effective health communication can help increase awareness in making appropriate health care decisions, and developing necessary skills in order to improve one's health status. Appropriate communication is vital in order for behavior change to take place to replace negative behavior. Behavior change requires knowledge, skill, and motivation. It is true that education can improve a person's knowledge base and skills, but that cannot be achieved if the individual does not understand how to obtain the knowledge or skills because of a literacy barrier. Once the knowledge and skills are accessible then the individual can determine if the perceived advantages of the behavior change are greater than the perceived disadvantages (Maldonato et al. 1995).

It is understood that health communication alone cannot resolve many of the systemic problems related to health literacy; however, it can help individuals better understand health-related information in order to make appropriate healthrelated decisions (HHS 2000). Healthy People 2010 has been instrumental in helping the healthcare world see the prevalence and importance of health literacy. Healthy People 2010 has made *health literacy* a priority as a national objective (HHS 2000; Mika et al. 2005).

The definition of health literacy that is most commonly used and widely accepted was given by Healthy People 2010, which is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Paasche-Orlow et al. 2005: 175). This definition includes both the importance of information and the availability of services. It encompasses not only reading ability but also the ability to understand and communicate important medical and health information (Neilson-Bohlman et al. 2004).

Several objectives in Healthy People 2010 address issues of health literacy such as objective 11-2, which is to improve the health literacy of persons with inadequate or marginal literacy skills. According to the National Adult Literacy Survey (NALS), 90 million adults have inadequate or marginal literacy skills, and most health education and promotion materials are written at the 10th grade level or above. There is a huge section of the population that is unable to effectively obtain and apply health-related information (HHS 2000). There has been a call for the development of appropriately written materials and education courses that are structured for persons with limited literacy skills. It has been recommended that one goal should certainly be to improve the literacy level of the general population through education with a supplemental goal of providing information in a format that is accessible for those with limited literacy skills (Nielsen-Bohlman et al. 2004).

Objective 11-3 calls for an increase in the proportion of health communication activities that include research and evaluation (HHS 2000). There is a need for effective health communication programs that are based on research and are evaluated. The success of these programs should be demonstrated through documenting the costs, scope and potential impact (Napalkov 1995). It has been documented by Healthy People 2010 that often people with the greatest health burdens have the least access to information, communication technologies, health care, and supporting services (HHS 2000). The first disparity is that people may not have access to the services needed to improve their health status. This may be due to the services not being offered or because of specific barriers that prevent access to those services. Barriers may include transportation, language, cultural differences, financial limitations, etc. The second disparity is that the services and programs may be available, but the understanding and comprehension levels of the individual are substandard, preventing access, and indicating limited health literacy.

It has been shown that people with limited literacy skills have difficulty in accessing services within the healthcare system and as a result have worse health outcomes than those with a higher level of literacy skills (Neilson-Bohlman et al. 2004). These disparities prevent success of health communication interventions typically among those with low education and low-income, and they remain less knowledgeable and less likely to change a negative health behavior (HHS 2000). Access to the health care system in the United States is difficult because it is "intricate, disjointed, and specialized" (Mika et al. 2005:351). The only way patients can effectively navigate the system and obtain the health services needed is to communicate with their health care provider, sign consent forms, understand treatment options, and follow the instructions to those treatment plans (Mika et al. 2005).

Health literacy is one disparity that prevents a large population from navigating a complex health system and prevents self-management of a healthy lifestyle (McCray 2005). The differences in the ability to read and understand health related materials can directly affects one's health status. For example people with low health literacy are more likely to report poor health, have an incomplete understanding of their disease and treatment, and even be more likely to be hospitalized (HHS 2000; McCray 2005; Parker 2000).

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There are specific tasks within the health care system that require adequate health literacy skills. Those demands are continually increasing because of the complexity of the health care system that include expectations for high levels of health literacy, reading, writing, and numeracy skills. These skills are imperative so that a person is able to schedule an appointment, fill out an insurance form, understand consent forms, explain a medical history, and understand and follow instructions for diagnostic procedures, treatment, and postoperative care (McCray 2005).

1.5.1.4 Institute of Medicine

In 2002 the Institute of Medicine organized the Committee on Health Literacy to conduct a four-fold investigation on health literacy. The first goal of the committee was to define the scope of the problem of health literacy. This included documenting the prevalence, effected populations, costs associated, and basic indicators of low health literacy, all of which would allow an assessment of the extent of the problem on an individual, community, and national level. The second goal addressed the improvement of health literacy among the public. This requires extensive research and eventual restructuring of the educational system and other obstacles within the health care system that prevent adequate health literacy to be generated. The Committee on Health Literacy also researched the current strategies that have been attempted to increase health literacy levels through public health interventions. The final goal included suggesting approaches to help promote health literacy, such as research or policy initiatives, interventions, or collaborations (Nielson-Bohlman et al. 2004).

The Institute of Medicine has recently published a study addressing the health literacy research already in motion along with recommendations of actions that would promote a health literate society. For example, the Institute of Medicine recommends matching the needs of the individual to the information and services that are available in the health care system. According to the study, there tends to be a mismatch between an individual's background, skills, and expectations and the information and services offered to the individual (McCray 2005).

1.5.1.5 National Assessment of Adult Literacy

In 2003 the National Assessment of Adult Literacy (NAAL) conducted another literacy survey similar to the NALS and found little change in the United States since 1992; however, the findings are not yet published. It was in response to Healthy People 2010 that the 2003 NAAL included the first-ever national assessment designed to measure health literacy in the United States. When the study is published it will be the most widespread direct study looking at the prevalence of low health literacy with a sample size of 19,000 Americans. The section that contains measurement of health literacy includes twenty-six healthrelated questions, which were embedded in the primary literacy assessment, and 10 health-related questions, which were added to the background section. Although the findings of this assessment are not available at this time, the healthcare community is awaiting the results. The presence of this test demonstrates the importance and possible effects of understanding the prevalence of health literacy (White et al. 2005; Mika et al. 2005).

1.5.1.6 Prevalence of Limited Health Literacy

The largest population survey that has been compiled on health literacy was published in an article, *The Prevalence of Limited Health Literacy* by Michael Paasche-Orlow (2004), which reviewed 85 health literacy studies that included data on 31,129 subjects and found that 26% had inadequate functional health literacy and another 20% had marginal health literacy levels. This suggests that 46% of the population had health literacy levels that were below adequate (Paasche-Orlow et al. 2004).

As a result of the past ten years there has been considerable research and attention to the topic of health literacy. This has aided in strengthening the relationship between education and health. It has been shown that "limited health literacy has been linked to problems with the use of preventive services, delayed diagnosis, understanding of one's medical condition, adherence to medical instructions, and self-management skills (Wolf et al. 2005:1946)." But, there is more work to be done. By understanding the full extent of low health literacy through the findings of NAAL appropriate interventions can be developed and properly evaluated in order to improve the health literacy of the population. This will aid those that have the greatest need of assistance and the least ability to access it because of their low health literacy and their high health burden (Nielson-Bohlman et al. 2004).

1.5.2 Health literacy assessments

Health literacy assessment tests are utilized to determine the different levels of health literacy. There are three levels at which individuals can be classified: inadequate, marginal and adequate (Gazmararian et al. 1999). Individuals with inadequate health literacy have the ability to perform simple, routine tasks with uncomplicated materials, but are unable to determine the correct dose of pediatric cold medicine from the information on the back of the package (Mika et al. 2005). Other examples of skills that would be difficult for an individual with inadequate health literacy include reading simple prescription instructions, understanding the results of blood sugar tests, and comprehending a reading passage at a grade level of 4.3 (Gazmararian et al. 1999).

Individuals that score at the marginal health literacy level are still considered to have limited health literacy; however, they are able to perform better on the simple tasks that are difficult for those with inadequate health literacy levels (Mika et al. 2005). They still showed poor comprehension of blood glucose tests, instructions for taking medications on an empty stomach, and had difficulty in reading and comprehending a passage measured at a 10.4 grade reading level (Gazmararian et al. 1999).

The final level of health literacy is adequate, and even though a majority of these individuals do very well on health literacy assessment tests, they still have

difficulty in interpreting more difficult numeracy tasks. There are varying degrees in each level of health literacy. The reality is that a person can be at different spectrums of each level. It does not mean that if a person is at an adequate level that they are able to do health related tasks at the same level as any other adequate level person. There are borderline cases that could truly go either way. Adequate level patients can have difficulty with some health related tasks, and some patients with inadequate levels have more difficulty than others. Much more needs to be understood then simply a health literacy level. Each individual is unique in the areas that they experience difficulty and each is unique in the way health literacy affects them.

1.5.3 Characteristics and Effects of Low Health Literacy

Health literacy is a complex variable that infiltrates and permeates all aspects of society. In the past, there has been an association between socioeconomic status and education level, which determined a person's ability in comprehending medical information. There is some validity in this assumption; however, it is not always true (Williams et al. 1995). Many studies have looked at the prevalence and effect of health literacy among specific groups, such as individuals with chronic illnesses (Gazmararian et al. 2003; Williams et al. 1998), older adults and the elderly (Wolf et al. 2005), Medicare enrollees (Gazmararian et al. 1999), and diabetics (Schillinger et al. 2002).

There have been specific characteristics that have been associated with limited health literacy, which could be considered as risk factors. Findings indicate that there is an obvious association between low health literacy and specific demographic characteristics (Paasche-Orlow et al. 2004). Some of the characteristics that are indicators or risk factors for inadequate health literacy include members of ethnic and cultural minorities, those living in the southern and western states of the U.S., those with less than a high school degree or GED, those with an age of 65 years or older, those with physical or mental disabilities (e.g., vision, speech, or hearing problems), and those who are prisoners, homeless or military recruits (Mika et al. 2005; Schillinger et al. 2002; Williams et al. 1998; Paasche-Orlow et al. 2004).

Unfortunately, it is difficult to know the true extent to which low health literacy is affecting these populations. Limited health literacy is an occult, silent disability (Williams et al. 1995). Many are ashamed of their illiteracy and hide it from their health care providers, friends and even their closest family members. Shame prevents them from asking questions or requesting materials written in a easier format to help them when they don't understand medication labels, medical forms, or self-care instructions (Parker 2000). Shame may also play a significant role in studies of health literacy, preventing a large (and probably highly-effected) population from being willing to participate.

Inadequate health literacy causes patients to have a poor understanding of the disease process, poor recall and comprehension of advice and instructions from the medical staff, and poor problem solving skills. This leads to negative health outcomes such as lower self-management skills, higher rates of chronic illnesses, and absence of preventative care (McCray 2005; Parker 2000; Chew et al. 2004 and Wilson 2003). The negative health outcomes due to limited health literacy are economically responsible for adding \$30-73 billion to the annual health care bill (Wilson 2003). For example, new Medicare enrollees with inadequate health literacy have a two-fold greater chance of hospitalization; diabetic patients with inadequate health literacy are more likely to have poor glycemic control and retinopathy, and persons with sexually transmitted diseases and inadequate health literacy are more likely experience barriers to treatment. In contrast, men with higher health literacy levels are diagnosed with prostate cancer at an earlier stage than those with low health literacy levels (Mika et al. 2005).

It is important to note that low health literacy is not synonymous with poor health. A person can go through their whole life with inadequate health literacy and never experience negative health outcomes because there is never a reason to go see the doctor. In the same degree, adequate health literacy does not indicate excellent health. Determining the relationship between limited health literacy and poor health is an important factor.

1.5.4 Age and Chronic Illnesses

The effect of limited health literacy becomes apparent when there is a need to access health care and a barrier, such as low health literacy is experienced which inhibits that ability. Individuals with chronic illnesses have more frequent opportunities to experience these literacy-related barriers than do other individuals. Chronic illnesses require self-management, including complex medication regimens, diet, exercise, and numerous doctor visits and testing (Gazmararian 2003). Because these illnesses require a person to be able to read, comprehend and take action based on health-related materials, low health literacy is much more detrimental in a chronically ill patient than it is in one that is generally healthy (Wolf et al. 2005).

Two of the populations that are at higher risk of experiencing negative effects of low health literacy are the elderly and those with chronic illnesses (Gazmararian et al. 1999). These are two populations that frequently overlap. According to Wilson (2003), 80% of individuals 65 years or older have at least one chronic condition. Fifty percent of those experiencing one chronic condition have at least two. It has also been noted that "the elderly are also the most likely to have the greatest health-related literacy needs because of the high prevalence of chronic disease in this age group" (Parker 2000: 278). It is unfortunate that at the same time many people become the most reliant upon the medical system, they experience a decline in literacy level (Wilson 2003).

As age increases, literacy decreases. The 1999 Gazmararian et al. study among Medicare enrollees was the first study to determine the relationship between age and health literacy, finding the prevalence of inadequate health literacy increased dramatically with age. In a population of 3,260, low health literacy increased from 15.6% of individuals aged 65-69 years to 58% of those aged 85 years or older. Wilson states possible reasons for this decline in health literacy can be the result of failing eyesight, diminished hearing, or declining mental alertness (2003). In addition, there are many more disadvantages that an older generation has with technology, which adds to the already existing barriers faced by this population as they attempt to actively participate in their health care (Gazmararian et al. 1999).

As age increases, so does the susceptibility to chronic illnesses. Daily treatment is a necessary part of chronic diseases, which requires appropriate skills and active participation from the patient. Not only do patients need to understand and cope with their disease, but also they need to detect symptoms that require medical attention, adhere to treatment schedules and prevent avoidable complications. It is the responsibility of the patient, but this can only be achieved if the patient is adequately informed and prepared from the medical, mental, physical, and social angles (Williams et al. 1998; Gazmararian et al. 2003 Schillinger et al. 2002; Nielson-Bohlman et al. 2004).

Although chronic illnesses were never listed as a characteristic of inadequate health literacy, there is a direct relationship between the two. In a study that looked specifically at health literacy among 3,344 older adults, participants with inadequate health literacy had significantly higher rates of certain chronic conditions compared to those with adequate health literacy skills. For example, in a multivariate analysis, inadequate health literacy was a significant independent predictor of having type II diabetes (18.7% vs. 12.8%) (Wolf et al. 2005).

Self-management practices and clinical outcomes in chronic disease care vary by the patients' level of health literacy (Schillinger et al. 2002; Williams et al. 1998). Effective disease management requires "systematic, interactive communication" between the patient and the provider (Nielson-Bohlman et al. 2004: 172). It has been documented that patients remember and understand less than half of what they are told by their physicians. Add in the deficiencies of limited health literacy, and patients become even less equipped to overcoming such gaps in understanding and memory when they get home from the doctor (Nielson-

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Bohlman et al. 2004). Patients with limited health literacy combined with chronic diseases show poor knowledge of their condition and the management of that condition. Not only do they have a greater difficulty in reporting medication regimens and the reason for the prescribed medications, but also they frequently have explanations of their disease that may interfere with adherence (Nielson-Bohlman et al. 2004).

1.5.4.1 Diabetes

There has been an extensive amount of research on type II diabetes and health literacy because type II diabetes has hit epidemic proportions within the United States. It can be described as one of the largest negative health outcomes of our society. The prevalence rate of type II diabetes has reached an estimated total population within the United States of 16-18 million people (Koch et al. 2002; Benjamin et al. 2003; Winer et al. 2004; Popoola et al. 2005; Mainous et al. 2004). It is estimated that by the year 2025 it will expand to 8.9% of the total population or 29 million people in the United States alone (Jones et al. 2004; Winer et al. 2004).

The most common complications with type II diabetes are heart disease and stroke, which account for 65% of all deaths among diabetics. This is perhaps due to the fact that 73% of all diabetics have high blood pressure. Type II diabetes is the leading cause of blindness in adults aged 20 to 74 years and accounts for 60% of all nontraumatic lower limb amputations. This is caused by damage to the nervous system, which can cause an impaired sensation or pain in the feet or hands, slowed digestion of food in the stomach, carpal tunnel syndrome and other nerve problems. Type II diabetes is also the leading cause of kidney failure, which results in dialysis, transplantation or death. Other complications include periodontal disease, birth defects, spontaneous abortions, excessively large babies, and biochemical imbalances that can cause diabetic ketoacidosis and hyperosmolar (nonketotic) coma (Jones et al. 2004; Winer et al. 2004; Mainous et al. 2004; Schmidt et al. 2003).

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Schillinger et al. (2002) published an article entitled *Association of health literacy with diabetes outcomes*, which examined the effect health literacy has on clinical health outcomes of diabetics. In the article, Schillinger et al. suggests that inadequate health literacy may contribute to the disproportionate burden of 16 million people with type II diabetes, many of which are among disadvantaged populations. He states,

From a public health perspective, health literacy may represent an important variable explaining the prevalence of poor health outcomes among patients with type 2 diabetes as well as some of the socioeconomic, racial, and ethnic disparities in diabetes outcomes in the United States (Schillinger et al. 2002: 480).

Health literacy could be a major factor in explaining the extreme health disparities among some groups like diabetics. There is a higher prevalence of poor health literacy among racial and ethnic minorities indicating that health literacy levels represent an important variable in explaining the increased incidence of diabetic complications such as diabetic retinopathy and blindness, end-stage renal disease, and lower extremity amputations (Schillinger et al. 2002).

A cross-sectional study of 408 diabetic patients in California found that 51% had limited health literacy skills and of that population 66% had a high school education or less. Overall those that had inadequate health literacy were more likely to have poor glycemic control and had a higher incidence of reported retinopathy and other diabetic complications. One explanation to this is their inability to recognize signs and symptoms associated with serious problems that need medical attention in order to prevent or divert a crisis, which may simply appear as non-compliance. Another explanation is that type II diabetes care requires a great deal of the patient self-management skills including self-monitoring of blood glucose, management of multiple medications, visits to multiple providers, maintenance of foot hygiene, adherence to diet and meal plans, and an active exercise program (Schillinger et al. 2002).

1.5.4.2 End Stage Renal Disease

It has been established that a considerable amount of research exists on the prevalence of health literacy and certain diseases such as type II diabetes; however, limited scientific information is available on the levels of health literacy within the ESRD population (Kleinpeter 2003). There have been no published studies examining the health literacy population of pre-ESRD patients in regards to their level of understanding required to chose a treatment option. Because of the complicated nature of written materials and oral instructions about medication dosages, dietary regimens, fluid management, and dialysis schedules, ESRD patients must posses an optimal level of health literacy for successful treatment. This study would fill the significant gap of research that exists within this population by examining the effects of health literacy.

The assessment of health literacy among pre-ESRD patients and the evaluation of the education program will demonstrate the effect of low health literacy and the role an education program can play in providing adequate information. This needs to be done quantitatively to understand statistically the prevalence, but also qualitatively to see the effect on an individual level. An anthropological study of the relationships between the doctor/dialysis staff and the patient demonstrates the impact of ESRD and the effect of low health literacy on this specific population. The frustrations and depression of the individual can be understood and the necessary changes can be implemented to make the quality of life better for the individual and ultimately for the ESRD population as a whole. This is an opportunity to turn research into practice by addressing a public health crisis and create a health education program that is appropriate for even those with limited health literacy.

1.6 Theoretical Approach To Study ESRD and Health Literacy

An anthropological approach to research requires triangulation between the problem, an ethnographic context and a theoretical orientation. This is achieved
through determining the problem and setting then choosing a theoretical orientation. Once these paradigms have been established, appropriate methodology for research can be selected. The perspective depends on what information is wanted and then what will be done with that information (Brown 1998). This is an anthropological study of suffering. It contains a holistic perspective of the interrelationships between mind, body, society, culture, and nature based on the experience of the individual (Dimou 1995).

A disease such as ESRD is experienced on multiple levels: macrocultural, microcultural, and individual. People individually and collectively experience illness at each level. The macrocultural level is expressed through large constructs such as the health care system and the effect on the economic system. This is expressed in the individual through social and political terms interpreted such as lack of power, inadequate resources or discrimination. The microcultural level is experienced by the individual through an understanding of the collective experience of the disease. Through the use of the Health Belief Model the experience of the disease is understood on a microcultural level (ethnicity, SES, family/co-workers) based on the experiences of the individual "such as their level of concern, motivation and previous experiences [can] be used to explain and predict behavior" (Armstrong 2003: 25). First person accounts (Explanatory Models) provide a construct of reality for the individuals. These constructs provide a framework for the patient and health-care provider that result in a better understanding and a more effective negotiation of treatment that is agreeable to both parties making it a collaborative effort (McElroy et al. 2003).

1.6.1 Explanatory Models

Based on an individual level approach an applied understanding of ESRD can be achieved through the documentation of an individual's Explanatory Model. *1.6.1.1 Illness, Sickness, and Disease*

Anthropologists have separated the meanings of illness, sickness, and disease in order to distinguish between them. John M Janzen has defined each

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meaning. He states that an illness is based on the perspective of the individual's experience of suffering. This may occur with or without the disease being identified by others and is defined by a culturally subjective definition that is expressed by the individual. This would be the individual's interpretation of the symptoms they are experiencing based on their cultural environment. Sickness, he states, is the subjective experience of suffering as defined by the society or as a group experience. This perspective is the social context that surrounds a person's illness, which suggests that illness is a collective experience. Janzen defines disease as a condition that is identified with a medical label and is recognized by the medical community, which is based on externally established signs despite the recognition of the suffering individual. This includes the scientific/biological perspective held by the *westernized* medical community (Janzen 2002).

There is a vast distinction between disease and illness; one being the biomedical perspective of the professional and the other is the layperson's interpretation of symptoms and causation. By looking at the phenomenology of illness or focusing on the person's experience with an illness, it gives the personal perspective or the point of view of the individual. However, illness isn't an isolating experience it is a social or community experience involving all those who interact with the individual. Although the individual experience of illness is typically the focus, it is acknowledged that there is a macrocultural, microcultural and individual perspective of how to experience health and illness, meaning that people respond both individually and collectively to health problems (McElroy et al. 2003)

There is a separation between the experience of the sufferers (culture/illness) and the professionals (objective knowledge/disease). An examination of illness without understanding it in its context is not only insufficient, but can be detrimental. The social course and personal experience of illness are analytically inseparable (Kleinman et al. 2002). The practitioner needs to seriously take into consideration the perceptions and ideas of the patient. It is especially important to gain insight into the patient's thinking when dealing with a chronic condition (Dimou 1995). This communication between the practitioner and patient can be effectively accomplished through the use of the Explanatory Model (Janzen 2002).

1.6.1.2 Explanatory Model Definition

Explanatory Model (EM) is defined as "the notion about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Dimou 1995: 155). An EM provides structure for a rapid and highly focused ethnographic investigation. It is concerned with the ways in which an illness episode is interpreted and understood by patients, healers (medical practitioners), and other members of the local social world (Brown 1998). The EM of the patient and the physician is based on each person's perspective of the etiology (cause or origin) of the disease or illness, the expected course, predicted outcome and the ideas about appropriate treatment (Kleinman et al. 2002).

Following are a list of questions that are used to assess the EM, which is applicable to any social actor:

- 1. What is the problem? Is it an illness? If so, what kind of an illness?
- 2. How does it affect the body-self?
- 3. What can be expected to happen next?
- 4. What will be the long-term outcome? Will it get better or worse?
- 5. What is most to be feared about this condition?
- 6. What treatment is most appropriate?
- 7. What is most to be feared about the treatment?(Kleinman et al. 2002: 237)

EM's help caregivers gain a rapid access to the experience of illness of the patient. However, it cannot replace a more comprehensive exploration of the social history of an illness and the life histories of the persons involved. In the context of extreme time-space compression that is found in the medical community, it is a

better alternative to the homogenized approach, which typically pushes cultural, moral and biographical meaning to illness experience aside (Kleinman et al. 2002).

The EM of the physician is based on biomedical information where as a patient's EM may include personal experiences, trama, and alternative explanations to the cause of their disease. The result is that many times the EM of the patient may be contrary to that of the physician, family members or other interested parties (Brown 1998). EM's are not fixed and static or removed from the continual negotiations within social life. Clinically this makes EM's useful because they are negotiable. The doctor that understands a patient's EM is better able to negotiate a shared understanding to form an agreeable treatment. This creates a bridge of understanding between the patient and doctor and provides the opportunity for the doctor to be empathetic (Kleinman et al. 2002).

In order to ensure success of utilizing the EM, genuine respect for alternative ways of thinking, feeling and being ill is vital. Objectivity and rationality of medical understanding should not be used in regards to EM's because they are moral formulations and should not be judged based on the same criteria as biomedicine. EM's are individualized and are an abstraction for much more dynamic social, personal, and moral processes (Kleinman et al. 2002). Ultimately it is when the difference between the illness (patient experience) and the disease (doctor diagnosis) is bridged, so communication can take place and together a treatment plan can be developed that will be effective. This communication can be accomplished through the doctor inquiring and attempting to understand the patient's explanatory model. Once the two perspectives are congruent then healing can begin (Dimou 1995).

1.6.1.3 Explanatory Model with ESRD Patients

Explanatory Models are an effective way to determine the modes of thinking of an individual, which can in turn be logically linked to a person's behavior (Brown 1998). By understanding a person's EM, communication can be exchanged on a deeper level based on the varying perspectives of patient and

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physician. The use of EM's to understand the causation of illness among patients experiencing End Stage Renal Disease could be advantageous. ESRD requires a complicated regiment of written materials on instructions about medication dosages, dietary regimens, fluid management, and treatment schedules. There are four different types of treatment that are available for ESRD, including hemodialysis, peritoneal dialysis, kidney transplant, and no treatment. Each choice requires careful thought and consideration because each has its own requirements, responsibilities, and consequences, which are expounded upon in the PrEP offered through SDS.

Based on Kleinman's Explanatory Model, the cause of the illness, meaning of symptoms, nature of the pathology, and the course of the sickness and treatment is determined from the perspective of the patient and medical staff. The Explanatory Model of the medical staff is presented through the PrEP, but until the doctors and staff understand a patient's EM, they will be unable to negotiate a shared understanding to form an agreeable treatment. Until there can be an understanding between the doctor and the patient, there will continue to be noncompliance from the perspective of the doctors and staff.

Although this study does not investigate a cross-cultural difference, it will be a cross-subculture comparison between the patients/participants of the PrEP and the doctors/staff of the dialysis center. The patients and the dialysis staff represent different Explanatory Models. The patient embodies the illness with extreme individual variations, and the doctor/staff utilize the PrEP to present their Explanatory Model of the disease of kidney failure. When there is disconnect or a separation between the doctor/staff and the participants, it results in low compliance of treatment and prevention. It is the expectation of the PrEP staff that the participants are "empty vessels" waiting to be filled with the scientific/technical knowledge about ESRD to become educated for prevention and treatment. Based on this perception, the PrEP staff is confident that the behavior of the participants

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will change and that the medical innovations will be readily accepted (Brown 1998).

The biomedical Explanatory Model of the physician/medical staff is shared during the PrEP to all those in attendance. As an anthropologist, obtaining the Explanatory Model of each participant is vital because it provides the opportunity to compare the EM of the participant to the EM of the physician/medical staff. There is a four-fold objective in obtaining a patient's EM. One, it allows the interviewer to recognize the perspective and understanding of the disease from the point of view of the patient. This is vital because it explains what the patient perceives and demonstrates a foundation of how a biomedical (PrEP) explanatory model can be understood. Second, it allows the patient to participate in his or her own health care. This results in empowerment, which in turn results into compliance (Napalkov 1995). Third, it can ultimately help the physician know if the goal of the physician and the patient are the same. The patient brings with them the personal interest and personal knowledge of their experience, and the physician brings with them the professional interest and specialist knowledge. Together the team, meaning the doctor, patient, family, friends and other health care professionals, can discuss the options and treatment plans available to determine what can be agreed upon. The final objective is to bridge the communication gap that typically exists between the patient and the physician. Only by gaining insight into the patient's thinking can there be hope of motivation and influence in a patient's behavior and attitudes (Dimou 1995).

The strengths of using Explanatory Models is the ability to understand the individual, personal effect of an illness. It gives a perspective that is more than just a statistical number; it gives a sense of reality. However, obtaining the EM of an individual is time consuming. The validity of qualitative information is sometimes questioned because of the inability of the qualitative data collection process to compare information across individuals. However, through the use of ethnographic methods emergent themes are seen, which cannot be understood through simplistic

evaluations. It is through obtaining a person's Explanatory Model that a deeper understanding of the impact across a population can be examined.

1.6.2 The Health Belief Model

The Health Belief Model (HBM) is used to predict the compliance of patients to prescribed treatments, based on the desire to avoid illness or that a specific action will prevent or alleviate the symptoms of that illness (Maldonato et al. 1995). Through the use of information obtained via the EM, specific information can be obtained. The HBM can give a greater understanding in explaining the reaction and perception to a disease and treatment which can establish an improvement in treatment adherence and quality of life (Krespi et al. 2004).

1.6.2.1 Components of Health Belief Model

There are six components to the (HBM). They include *perceived susceptibility*, *perceived severity*, *perceived benefit*, *perceived barriers*, *cues to action*, and *self-efficacy* (Janz et al. 2002). Based on the concept of the Health Belief Model, the only way behavior change will take place is through the feeling of being threatened by current behavior patterns and through the belief that change of a specific kind will result in a valued outcome at an acceptable cost. This will only occur if the individual feels competent in overcoming the perceived barriers through their knowledge and skills (Janz et al. 2002).

The first component, *perceived susceptibility* is defined as one's belief in the likelihood of experiencing a condition that would adversely affect their health. Understanding the perceived susceptibility would explain how a patient accepts or denies a diagnosis, through understanding the risk factors associated with that disease. The *perceived severity* refers to the belief of the individual in how serious a condition/illness could affect him or her. This includes the medical and clinical consequences such as prognosis, pain, potential disability, loss of independence, as well as the social consequences of the disease including how it will affect family, work, and social relations. *Perceived susceptibility* combined with the *perceived* severity creates the *perceived threat* (Janz et al. 2002).

Once the patient accepts the *perceived threat*, it produces a force that leads to behavior, but the action is determined by the beliefs of the individual dependent upon the *perceived benefits* that will reduce the disease threat. This is based on the belief that efficacy in the advised action will reduce the risk or seriousness of the impact such as improving the quality of life or preventing certain symptoms. This is counter-balanced by the impediments or *perceived barriers* that prevent a certain action from taking place. This is similar to a cost-benefit analysis: an individual makes a decision according to whether or not they believe the outcome of the prescribed behavior outweighs the cost of replacing the negative behavior, or whether or not the barriers be overcome in a way that it makes the new behavior cost effective (Janz et al. 2002; Bartlett 1995).

In order for the process of determining the perceived threat and the cost benefit analysis to take place, there first has to be a *cue to action* that will instigate the behavior. This can be something as simple as seeing a commercial, attending a health educational class, receiving a biomedical marker from blood work, or being hospitalized. But it is only through *self-efficacy* that progression in the prescribed behavior will take place. *Self-efficacy* is the confidence in one's ability to take action. It is not simply the acquiring of skills, but the confidence to successfully execute the behavior and to have the desired outcome. This is typically achieved through education and skill building and results in a reduction of anxiety (Janz et al. 2002).

1.6.2.2 Application of the Health Belief Model

An example of the application of this theory can be seen in an article by Janet L. Welch (2001) entitled *Hemodialysis Patient Beliefs by Stage of Fluid Adherence*. Welch uses the Health Belief Model to explain why dialysis patients have difficulty adhering to the strict guidelines of less than 1 kg of weight gain between treatments, using eight benefits of compliance, and seven perceived barriers.

The benefits of compliance of fluid adherence include decreased edema, absence of shortness of breath, reduced muscle cramping, lower blood pressure, and ability to breathe better, which all lead to decreased risk of hospitalization. The perceived barriers include social situations, time, embarrassment, activity interference, forgetfulness, and strict adherence to doctor's orders. These benefits and barriers are the basis for measuring the seriousness and susceptibility that is perceived based on the individual's perspective.

The effect of the Pre-renal Education Program can be seen through the application of the Health Belief Model. Choosing to attend the class is the first sign of the individual's *perceived susceptibility*. It is the assumption that their presence in the class suggests a high perceived susceptibility to ESRD. Attendance at the class demonstrates some acceptance of the diagnosis and an interest in learning more about the treatment options available. However, another possibility for attendance could be due to social support or pressure. This could be from their physician, family member, or friend. This suggests the power of the social support system and the ability of overcoming obstacles (Janz et al. 2002).

Not everyone invited to the PrEP accepts the invitation. This may be that they are in denial of their susceptibility to ESRD and may think that their kidney function levels will improve. Based on a conversation with Nurse 1, she has noticed an increase of those attending the class in the past year as well as a more positive response to the invitation to the class. She attributes this to the preparation and involvement of the nephrologists in increasing the perceived susceptibility of the patients in helping them realize the reality of their diagnosis.

Many receive the diagnosis of ESRD and have a fatalist *perceived severity*. Many believe it is a "death sentence" or that it will destroy their quality of life. A majority of those types of attitudes are due to misinformation and lack of education. Others have a clear understanding of their perceived severity as reflected by their kidney function level and how quickly it is approaching 15%. There are many different attitudes that are reflected in the approach that the PrEP is given. However, many come not expecting to find any benefits in the class, but are surprised to realize that there are options available to them.

Choosing the type of treatment is a difficult aspect of the diagnosis of End Stage Renal Disease. It is the acknowledgement that life before ESRD is over and now 15 or more hours a week will be spent sitting in a chair surrounded by others in a similar situation, or going through 36 different steps to hook up to 6 feet of tubing for 9 hours during the night. There isn't a desirable treatment option for ESRD, but the alternative is death. From the different types of treatment options present, a patient must find the one that fits into their lifestyle the best. Examples of some *perceived benefits* of taking PrEP might simply be the delay of doing dialysis for a short time, the freedom to choose the type of dialysis that would best fit into their lifestyle, or that dialysis isn't a death sentence.

The *perceived barriers* are the most powerful single predictor of behavior, because they control everything (Maldonato et al. 1995). However, if those barriers are removed, progression is likely to take place. Individuals with ESRD experience many barriers that prevent them from choosing certain treatment options. Examples of barriers include transportation, inconvenience, progressive poor health, power outages, lack of understanding (health literacy), and fears. There is so much knowledge that needs to be understood in order to have a successful dialysis treatment. Attendance of the PrEP can help eliminate many of these barriers not only for the information they gather, but also for social networking that allows them to have contact with the dialysis staff to ask questions now and the future. The PrEP staff is designed to help eliminate barriers of transportation, education, insurance, diet/nutrition, and social adjustment (Janz et al. 2002).

Attendance at the PrEP also provides an opportunity for *cues to action*. Taking a tour of the dialysis facility is a unique time for these potential dialysis patients to see into the future. It triggers a moment that makes them want to do anything to delay dialysis, be more compliant in taking medication, controlling diet, or listening more to the doctor. However, this cue to action would be worthless if there wasn't a portion of self-efficacy available to the individual before leaving. The purpose of PrEP is to inform and build the skills and resources needed to have a successful treatment. This not only includes the knowledge about dialysis, but also diet, emotional adjustment, medication and overall knowledge about the kidneys. The best way to eliminate fear is to show what will take place. By showing the PrEP participants the dialysis unit, it allows them to prepare themselves for the future. They are able to talk to current dialysis patients and ask them questions.

The strengths of applying this model to the effect of the Pre-renal Education Program is that is allows us to understand the power and results of education through the ability to make appropriate medical decisions. HBM is an effective source of explaining behavior change and understanding how to create an optimum environment for that behavior change, which prevents negative health outcomes. However, if an individual has such a low level of perceived susceptibility that they don't attend PrEP, behavior change will not take place. The only recourse available would include the physician increasing the perceived susceptibility of the patient, which can be difficult to achieve if there is a lack of knowledge or the Explanatory Model of the patient is not in accordance with the Explanatory Model of the medical staff. Unseen barriers may also prevent a patient from attending PrEP, and if those barriers are not resolved progression will not take place.

1.7 Research Questions

Based on the premise established in the literature review, there is a higher prevalence of low health literacy among the elderly, and negative health outcomes are worse for those with chronic illnesses and low health literacy. There is also a need for pre-ESRD patients to be well informed of the consequences of their disease and the treatment options available. The proposed study seeks to answer the following questions:

- What is the prevalence of low health literacy among PrEP participants at Samaritan Dialysis Services?
- What are demographics and characteristics of PrEP participants at Samaritan Dialysis Services?
- What are the participants' perceptions of the Pre-renal Education Program's effectiveness in terms of educating them about ESRD at Samaritan Dialysis Services?

What is the prevalence of limited health literacy among PrEP participants at Samaritan Dialysis Services? This will be the first study that will document the prevalence of limited health literacy among pre-ESRD patients attending an educational course. This study will establish whether or not a deficiency of health literacy exists within this population. This is an important population to research because of the complicated nature of End Stage Renal Disease. The consequences of not being able to understand the complicated nature of this disease are serious and can result in death.

What are demographics and characteristics of PrEP participants at Samaritan Dialysis Services? This is a population that has not been studied in correlation to their levels of health literacy. Due to the type of choices available and the requirements of pre-ESRD patients, it is imperative that a better understanding of this population be established. Once demographic information about this population is colleted, then correlations between demographics and health literacy levels can be determined.

What are the participants' perceptions of the Pre-renal Education Program's effectiveness in terms of educating them about ESRD at Samaritan Dialysis Services? In the past there have been positive perceptions of the PrEP, but it has not been evaluated or documented. The effectiveness of the program will be determined through the documentation of comments from the participants and the measurement of trends in treatment choice as well as other changes in behavior.

CHAPTER 2: PRE-RENAL EDUCATION PROGRAM & SAMARITAN DIALYSIS SERVICES

2.1 Samaritan Dialysis Services

The Pre-renal Education Program (PrEP) is an education program for patients with End Stage Renal Disease and is offered at the Samaritan Dialysis Services (SDS) located on the campus of Good Samaritan Hospital in Corvallis, Oregon. SDS is an independent multidisciplinary dialysis facility offering the expertise of health care providers, dialysis technicians, social workers, and dieticians to patients diagnosed with End-Stage Renal Disease (ESRD). The Samaritan Dialysis Center has a total of 110 dialysis patents. There are forty-eight patients in Corvallis and thirty-two in Lebanon, which consists of 73% of the dialysis patient population. The other 27% (30 patients) are peritoneal dialysis (PD) patients.

2.2 Referral System

The experience of End Stage Renal Disease begins with the primary care provider referring patients to a nephrologist (kidney specialist) (see **Figure 2**). This typically occurs when the physician notices symptoms, signs or other potential complications with the kidneys such as a decrease in kidney function levels. The nephrologist then refers the patient to the PrEP when kidney function levels reach 25% or below, or if there is a rapid decrease in kidney function levels. This is individually based because each patient has their own symptoms, cause of illness and progression in the disease. After a patient attends PrEP and kidney function levels reach 15%, a patient must make a treatment choice.



Figure 2. Flowchart of PrEP Referral and Treatment Network

2.3 History and Mission of PrEP

In 1998, Samaritan Dialysis Services (SDS) initiated the Pre-renal Education Program (PrEP) to help pre-ESRD patients understand the choices of treatments available, costs involved, diet restrictions, and how to cope with this new disease. The development of this educational program has been a grassroots effort by the administrator of SDS. She experienced a similar class in a previous dialysis center, and when she transferred to Corvallis to begin a new center, she felt that it was an important class to implement. It started out as a one on one class with a flipchart and developed into slides. Since that time the class has been modernized and uses a PowerPoint presentation, which provides the participants with a more pleasing visual experience. The class is based off of an educational program offered by the Baxter Patient Education Program entitled "Choices" using the PowerPoint presentation created by Baxter, a dialysis supply manufacturer. The PrEP has a two-fold mission:

- Educate participants about ESRD and treatment options
- Prepare participants for the future through adjustment and planning

Educating participants about their disease helps alleviate the fear of the unknown. Many enter PrEP with the fear that ESRD is a death sentence. By allowing potential dialysis patients to see other dialysis patients, it can have a powerful effect on changing the patient's view of the prognosis of their disease. Education also enables them to make an informed decision on which type of treatment would best fit into the context of their lives. The skills and information gained from PrEP help the participants know that there are things that they can do now to protect their kidneys that may prevent future damage and might delay dialysis for a little longer.

2.4 PrEP Course Content and Material

The Pre-renal Education Program (PrEP) curriculum includes eight topics: introduction of kidney functions, hemodialysis (HD), tour of the dialysis center, transplantation, no treatment option, peritoneal dialysis (PD), diet, and adjustment (coping and lifestyle issues). The presenters include the coordinator, Nurse 1 (RN), Nurse 2 (Peritoneal Dialysis Charge Nurse/RN), the Medical Social Worker (MSW/ LCSW), and the Clinical Dietician (RD/LD).

2.4.1 Introduction

The coordinator, Nurse 1, begins each class by giving a brief overview of what will be covered in the next couple of hours. By using a PowerPoint presentation provided by Baxter (a manufacturer of dialysis products) she begins by giving a brief summary of the function of the kidneys. Through the use of colorful drawings of kidneys, toxins, blood, and bodies, Nurse 1 is able to give a basic foundation of the functions of the kidneys. Even though the slides have words on them, Nurse 1 does not read them. Instead, she talks about the slides and explains them. This enables her to look right at the participants and verify a level of understanding. Throughout the presentation she addresses the typical concerns that most pre-dialysis patients have. This helps the participants feel that they are "normal." Within the group setting, individuals are able to ask questions that others might not feel comfortable asking. Surprisingly, most participants share private medical information. It is a relaxed setting where participants are able to ask questions during the presentation, and there seems to be a sense of understanding among the participants based on the heads nodding in agreement to the information presented.

2.4.2 Hemodialysis

Next, Nurse 1 presents the first treatment option of End Stage Renal Disease, which is hemodialysis. Hemodialysis is the most common form of dialysis used in the United States. It is done by replacing the kidneys with a machine that acts as an artificial filtering membrane through the use of a special cleansing solution that removes waste products and excess fluids from the blood stream.

It is the type of dialysis that is performed in a dialysis center by staff nurses or technicians. The treatment takes between three to five hours, depending on the size, and blood mass of the individual. It must be done three times a week. The morning shift begins at 5:30-6:30 and lasts until 9:30-10:00. The afternoon shift begins at 10:30 to 11:30 and runs until 2:30 with the last people off at 4:00. A person can choose from two schedules; Monday, Wednesday, Friday or Tuesday, Thursday, Saturday.

One aspect of hemodialysis that very few patients are prepared for is the "fistula." This is an access, which is created in the patient's arm (or sometimes a leg) by a surgeon. This access joins an artery to a vein and is called a fistula or a graft. Each time a patient undergoes hemodialysis, two needles are inserted through the skin to gain access to the bloodstream via the fistula. The blood is then sent through the dialylzer (the filter), which is a hollow, clear plastic tube, twelve inches long. It is filled with fibrous strands that filter the blood as it passes

through. The information about the fistula is typically the most difficult information for the participants, because many of them come unprepared for the knowledge that they will have to be poked with two needles three times a week.

It is the goal of the dialysis staff to have a fistula in place for at least three months before beginning dialysis or when kidney function levels are at 25% so that the fistula has time to "mature" before it can be used. Few realize that it will be necessary for them to do this surgery before dialysis can begin, thus emphasizing the importance of this class. Nurse 1 explains that a temporary access (a catheter) can be put into the neck; however, there is an increased risk of infection.

Nurse 1 passes a dialylzer and a temporary catheter around for the participants to hold and touch. The use of these visual objects create for many the realization that a similar catheter may soon be placed next to their own clavicle, or that a similar dialylzer will soon have their blood filter through it.

2.4.3 Tour

The greatest teaching tool comes when the participants take a tour of the dialysis facility. As the attendants of the class enter into the dialysis facility, they see twelve hemodialysis stations with the patients in recliner chairs. Some are watching TV; others are sleeping or reading. It amazes many of the participants that they aren't in pain or uncomfortable. The atmosphere of the room is relaxed and pleasing to the eye. Large windows surround the room looking out over the tree-covered hills that are typical of the Oregon Willamette Valley. Many participants fail to see the beauty and instead turn their backs to the dialysis floor, as they stand in the doorway. Some need a moment to compose themselves, and others need a minute to sit and take a deep breath. One participant in the class stood in the doorway ready to faint and throw up. After a little while of her saying, "I can't do this," she finally took a deep breath and said, "Okay, I'm okay." Eventually participants make their way into the room, and the class gathers around a patient doing hemodialysis.

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Using a patient as a visual, Nurse 1 demonstrates how the catheter and the fistula work on the actual patient. She helps them follow the blood out the body, through the tubes, and filter through the dialylzer. She points out how there is a separation of the waste and blood and how the blood enters back into the bloodstream. Participants are then able to talk to the patients and ask them questions. The most common questions are "Are you in pain?" or "Are you cold?" Some participants don't ask any questions. They just stand back and absorb the situation. It is here that many realize that dialysis is a replacement treatment, not a cure.

2.4.4 Transplantation

After the tour, Nurse 1 covers the topic of transplantation. Typically not much time is spent on this area, because most of the participants are not eligible for a transplant due to serious health conditions. For those who are, Oregon Health & Science University (OSHU) offers a kidney transplant class that helps kidney patients and their families who see transplantation as a viable option. There are two sources from which a person receives a kidney, either through a live donor or a cadaver. In order to be considered for a kidney transplant, a patient must first have a referral letter from their nephrologist. At that point OSHU will arrange for an evaluation and health screening which takes two days. Following the evaluation, the transplant team determines whether or not a person can be placed on the transplant list based on the findings of the tests.

2.4.5 No Treatment

Nurse 1 then points out that patients can also choose to do "no treatment." This is not an option that should be taken lightly, because it means that the disease will be fatal once the kidneys completely fail. It is important that all options should be taken into consideration and appropriate people should be talked to such as family members, nephrologist, clergy, dialysis social worker, and dialysis staff. This again reinforces the importance of this educational program. The decisions being made by these participants are life-altering or life-ending decisions. Once the information is given and understood by the participant and the no treatment option is chosen, the dialysis staff will support that decision.

2.4.6 Peritoneal Dialysis

Nurse 2 then presents the information about the final treatment option, peritoneal dialysis (PD). This is a treatment option that is done in the patient's home. Instead of using an artificial filter like in hemodialysis, the patient's own peritoneum is used. The peritoneum is a thin membrane that lines the abdominal cavity. The way that it is accessed is through a catheter, which is placed in the lower abdomen. The process is achieved by passing a special fluid, dialysate, into the peritoneum cavity through the catheter where is sits or dwells for a period of time. During this time, toxins and excess water are drawn across the peritoneum membrane and out of the blood stream into the dialysate liquid. After a period of time, the fluid is then drained through the catheter and is replaced with fresh fluid where the process is then repeated.

There are two types of PD: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Continuous Cycling Peritoneal Dialysis (CCPD). CAPD is the most common. It does not require any machines but instead uses gravity. Exchanges (draining old fluid and replacing it with new fluid) are done during the day four to five times a day and each exchange takes 20-40 minutes. CCPD is similar to CAPD but is done during the night while one is sleeping by using a machine called a cycler. The cycler circulates the fluid in and out of the peritoneal cavity throughout the night for eight to ten hours.

Nurse 2 uses several visual aids to assist in the explanation of this treatment option. She shows a bag of dialysate and the coiled catheter that is implanted into the abdomen with the titanium cap that helps prevent infection. However, there is a risk associated with PD, a condition called peritonitis that is painful and serious if not treated. This risk is avoidable through strict demands on cleanliness. The prospect of peritonitis worries many participants and is the main deterrent to choosing PD. There are many advantages and disadvantages to each of the treatment types. A unique aspect to the treatment of ESRD is that a treatment option can be chosen that best fits the lifestyle of the individual. None of the choices are very convenient; however, some fit into the life of an individual better than others. For example, if a person is still employed, it would be very difficult for them to leave the office three times a week four hours at a time. To them it may be a burden to have to go into a center three times a week for four hours, but to others it may be a relief to have someone else responsible for their care. Some look at their dialysis treatment as they would a job. They leave all of their work at the "office"—or at the dialysis center—so as to not disrupt their life as much.

2.4.7 Diet—Nutrition, fluid management and medications

There are several aspects to the diet portion of the presentation that makes it complicated. There are different diets associated with pre- verses post-dialysis, and hemodialysis requires different constraints than peritoneal dialysis. The expectations of the participants include education about what can be done to prevent future damage to the kidneys, and what they should expect once they begin dialysis. Many come into ESRD already watching their diet and taking medications. The dietician begins by asking, "Who is already on a diet prescribed by a physician?" Many are diabetic and are watching their sugar levels, and others are on low protein or low sodium diets. Others should be on a diet but admit they don't follow it very well. Once she has established the current situation for each participant, she goes over the different types of diets they might experience.

Because the kidneys are no longer functioning in a renal patient, certain foods need to be avoided or limited. Participants specifically need eat the right amounts of protein, potassium, phosphorus, and sodium. Each one of these types of foods not only affects the current way pre-renal and renal patients feel but also affects the success of dialysis treatments.

Since dialysis patients have no way of excreting fluids except through dialysis, it is important for them to limit the amount of fluid they consume. There

is a direct correlation between fluid weight gain and physical comfort during and after dialysis. The dialysis machine has to work harder to remove that fluid, which results in an uncomfortable, longer treatment causing muscle cramps and changes in blood pressure. Even before dialysis begins, it is important to for patients with ESRD to limit their fluid intake. As the kidney function levels decrease, urine output will decrease as well. In order to limit the amount of excess fluid on the body and prevent negative health outcomes such as edema, only four cups of liquid should be consumed per day. Those that still have urine output can drink four cups of liquid more than their urine output. For example if a person's urine output is two cups a day adding four cups of liquid to that comes to a total of six cups of liquid that can be consumed per day. This too is a difficult regiment to adhere to.

The final portion of the nutrition section that is covered by the dietician is about medications. Vitamins and minerals are important for good health. Patients on dialysis need special vitamins because kidney disease changes their needs. Vitamins available for dialysis and pre-dialysis patients are specially formulated to replace much of what the kidneys are no longer able to produce, such as iron, vitamin C, B complex, and vitamin D combined with calcium. Another common medication taken by pre-dialysis and dialysis patients is a phosphate binder. It has to be taken with the food that contains phosphorus, which sends some of the phosphorus through the stool. If blood phosphorus levels get too high it will pull calcium from the bones causing the bones to weaken. Many participants are already taking a phosphate binder but are doing so incorrectly causing it to be ineffective.

2.4.8 Adjustment

The social worker is the final presenter in the class. First she talks about money and insurance. She explains that Medicare covers 80% of all costs associated with dialysis. The cost of hemodialysis is \$6,500 to 10,000 a month and transplantation costs \$80,000. If a live donor is used Medicare also covers the medical costs of the donor at 100%. At this point that social worker asks each

person what type of insurance he or she has. Almost everyone says Medicare, but there is occasionally someone that is too young to qualify for Medicare. Since 1973, people diagnosed with ESRD qualify for Medicare once dialysis begins, but it is still imperative to have a secondary insurance to cover the 20% not covered by Medicare. If there is anyone in the group who doesn't have a secondary insurance she sets up an appointment with them to search for an appropriate secondary insurance.

Many find comfort knowing that their insurance will absorb a majority of the cost, and they are able to focus on the adjustments that will need to take place in their lives. The social worker discusses six topics, which contribute to patients' successful adaptation to lifestyle changes that come with dialysis. They are education, professional help, communication, attitude, sense of humor, and activity. Each is vital to having a successful treatment. The social worker invites anyone is having trouble coping with their new disease to seek her assistance.

The PrEP is an opportunity for patients with a diagnosis of ESRD to realize the perceived susceptibility and severity of their disease, to realize the benefits of treatment, overcome any barriers, and gain self-efficacy in the ability to make and comply with a treatment choice. For those that are having difficulty in realizing the susceptibility and the severity of their disease, PrEP includes many opportunities for cues to action that can be a motivating force in order to encourage behavior change.

2.5 Case Study: PrEP Impact

There are varied responses to the impact of the Pre-renal Education Program all of which have been positive, with occasional suggestions of how it could be improved. It is interesting to watch as the class ends and the participants leave the room. Some typically linger for a few minutes and ask questions of the dialysis staff. For example, a 75-year-old male, who already had a fistula in place, with kidney function levels at 10%, stayed after the class, and talked to Nurse 1 about his fistula, since she is the "access coordinator." He couldn't recall exactly when he had it put in, but he thought it was about two months ago in Salem, and that it needed a couple more weeks to mature. After they chatted for a while, they began talking about when he would start dialysis. First Nurse 1 talked to him about which treatment he would choose, and when he said that he had decided on hemodialysis she then asked him how soon he would like to start. It was obvious that he had some fears regarding dialysis even after taking the class. Nurse 1 could sense this fear and asked what his greatest fear was, and he just replied, "All of it." She asked him what symptoms he was experiencing and how he felt overall.

After a while Nurse 1 thought it would be best if they called his nephrologist to see if they could start him on dialysis the following day. They decided they would try to use his fistula and if it didn't work they would take him over to radiology and give him a catheter to begin dialysis immediately. It seemed as if this class gave him the courage and opportunity to start dialysis at that point before his symptoms and condition became worse. Based on earlier conversations with this participant, I think that the catheter was the point that prevented him from starting sooner. From the class, he realized that the catheter wasn't going to be too painful to receive, and that the fistula would possibly be mature enough to use immediately. Not only did the participant gain the courage to start dialysis by eliminating fears through education, it also gave him the necessary contacts in order to perform the necessary tasks.

CHAPTER 3: METHODS AND ANALYSIS

This study uses both quantitative and qualitative data collection and analysis methods. These methods include participant observation, individual interviews, evaluation of Pre-renal Education Program (PrEP), and S-TOFHLA. Individual interviews provide an opportunity to ask questions to learn about the patient's Explanatory Model. Individual interviews are important in learning about the effectiveness of PrEP, and the S-TOFHLA, as a quantitative measurement, determines the health literacy level of each participant.

A major limitation of this study is the inability to measure the long-term success of the program. Due to this limitation of time and resources to measure success, this study focuses on the specific feedback from the participants in regards to their comments about the class as well as specific behavior they were motivated to change.

3.1 Research Design

The research design of this project was set up to evaluate the Pre-renal Education Program and determine the prevalence of low health literacy. The appropriate paper work through the IRB (Institutional Review Board Approval #2954) of Oregon State University and through the Samaritan Dialysis Services, LLC was completed and approved. Gathering informants took place during a seven-month period beginning in August of 2005 through February of 2006. Broadly, the data collection followed the steps in **Figure 3**.



Figure 3. Research Design: Cycle of each participant

3.1.1 Invitation to PrEP/ Participate in the Study

Potential study participants were informed about the study during the invitation call to the PrEP from the coordinator. The PrEP nurse briefly informed them, with a scripted outline, about the aims of the study and explained that their participation was on a voluntary basis. The study sample is primarily a convenient sample. The limitation of representing all ESRD patients is that only the most interested patients agreed to participate in the study. There are several reasons for the low participation rate, which should be addressed. First, the method of obtaining the sample was problematic. The first exposure of the study by the potential participants was during the invitation call to the PrEP from the coordinator. This was a difficult task for Nurse 1 because of the sensitive nature of End Stage Renal Disease. There have been times that the patient was unaware that their kidney function levels were low enough that they should be considering dialysis, or that they were going to be invited to the PrEP. Other times, potential participants felt overwhelmed with the idea of spending four hours in a class and having the addition of speaking to a researcher two other times. Based on the feedback from Nurse 1, it was difficult to "sell" them on the class and the research project. She felt like a telemarketer when obtaining permission to have me call them.

The second limitation of the sample was timing. September and October was a time of vacation for many of the presenters of the PrEP. This resulted in the social worker contacting participants of the PrEP and asking them to participate in my study. Due to a lack of communication, this did not happen and I had a low participation rate during these months. Since the invitation to attend the PrEP occurs in advance of the class, there were three months (September, October, and November) that my participation rate was at 23%. The remaining months (August, December, January, and February), I had a participation rate of 77%.

Since the sampling was based on convenience, it is probable that my findings are skewed. It is likely that those with the lowest levels of health literacy would be the least likely to be interested in participating. However, all studies that deal with health literacy levels have been based on convenience, and as such, the findings of this project should be valuable in relation to the existing body of knowledge about health literacy.

3.1.2 Interviews

The interviews with the participants are an important aspect of this study because it provides the opportunity to understand their disease (ESRD) from the perspective of the individual. They included interviews before attendance to the PrEP, and then once again after the participant attended PrEP (see Appendix A).

After Nurse 1 obtained the permission for me to contact the participants in regards to the study, I contacted each one by telephone to set up an appointment for the pre-interview. During this phone conversation, I answered initial questions or concerns about the study. The major limitation to this portion of the research design was time. There was typically little time between the invitation to the PrEP and the day of the class. The majority of the interviews took place in the participant's home. Many were relieved to understand I would come to their home instead of meeting them at the dialysis center.

3.1.2.1 Informed Consent Document

At the beginning of the interview, in the home of the participant or another neutral location, I explained the study procedures and research process and provided detailed information on the informed-consent process as approved by the Institutional Review Board of Oregon State University Approval #2954. Each participant (and anyone else involved in the interview from their support network) was given the opportunity to ask questions. After all questions were answered the participants were given an informed consent form to be signed, which was witnessed and dated. Participants received a copy of the signed informed consent form. There were no concerns regarding the informed consent form, and all participants understood the concepts as explained in the consent forms. I felt it was extremely important that the form and concepts be easy to understand because of the topic of this study (health literacy). I began each interview asking if I could explain the document to them. Due to the limited health literacy of some of the participants, I explained the form topic by topic, rather than having the participant read it. There were two exceptions, an English professor, and a lawyer felt more comfortable reading it rather than having me explain it to them.

3.1.2.2 Pre-PrEP In-person Interviews

The goal of the pre-PrEP in-person interview was to obtain the participant's Explanatory Model (EM), which documents the knowledge and understanding of their health condition. This interview session took place before participating in the PrEP and included both closed-ended and open-ended questions. It was designed to assess the perceived health status of the individuals and to collect relevant demographic information.

The interview began with basic demographic questions, such as age, ethnic background, homeownership, education level and location, and current family setting. These questions helped to establish a possible correlation of characteristics and the effect on the relationship between health status and health literacy levels. This was also a time of observation of those activities in the home that deal with applying the self-management health skills needed to handle their personal health care. Self-management skills examples included, seeing the method of compliance of taking current medications, and organizational skills of doctor's appointments. It was also an appropriate time to observe relationships of support networks available to the participant. Unfortunately not all interviews were conducted in the home, and I resorted to specific questions about medication compliance and family support.

After demographical questions were answered, I asked questions in order to obtain an anthropological perspective of their illness through the Explanatory Model (EM). Obtaining the EM began by asking the informant, "What do you call the illness you are experiencing?" Using the term expressed by the informant I would fill in the blank and ask the following questions.

- Tell me about the experience you have had in regards to ______,
 for example, the experience with your doctor, family."
- What does this _____ mean to you?
- What does it mean to your family?
- What do you think has caused _____?
- Why do you think it started when it did?
- What do you think ______ does to your body (symptoms)?
- How severe is _____?
- What do you believe will happen with this sickness?"

Some of the informants would expound for 20-30 minutes explaining from their childhood what he or she had experienced resulting in their current illness. Others needed several prompts in order to generate a flowing narrative, or would simplistically answer, "It is genetic." It is the goal of these interviews to determine the Explanatory Model of the PrEP participants and to see if there is any change in their knowledge based on the education class that is presented. Understanding a person's EM allows the ability to know whether non-compliance is due to differing perspective or inability to understand the information that is presented. It is believed that improving communication and understanding between the two EM's of the patient and doctor that compliance or adherence to the appropriate treatment will increase. This is based on the thought that a person's behavior is logically linked to their modes of thinking; therefore, it is essential to know what people think in order to effectively communicate with them (Brown et al. 1998).

The remainder of the questions for the pre-PrEP interview revolved around the current information that the participant had in regards to dialysis and End Stage Renal Disease. Questions regarding current kidney function levels were a good indicator of the amount of information provided by the physician that was actually understood by the participant. By comparing the chosen type of treatment before and after PrEP, the effect of the class could be determined as well as the participant's source of information about ESRD and treatment. The final questions involved expectations of the class and current concerns or barrier experienced.

As mentioned before, the length of the interviews varied drastically. Many of the participants in this study were elderly people that were lonely and eager to talk. Much time was spent building rapport through conversations about their lives and circumstances. Some interviews lasted for 15 minutes and others lasted up to two hours. I enjoyed meeting the incredible people that were gracious enough to allow me into their homes and into their lives. Many shared extremely personal information with me, and trusted me with the intimate details of their lives.

3.1.2.3 Post-PrEP In-person Interviews

The post-PrEP interview took place after the participant completed the PrEP education course. It was an opportunity to discuss the participant's overall impression of the educational program. Since rapport had already been established in the previous interview, it was a perfect occasion to collect information from the participant. I completely enjoyed going back to the homes of the participants, as if I were visiting a good friend to find out how they were feeling or experiencing their

current situation. Once again, the interviews were set up through the telephone, and the interviews took place in their homes or at a neutral location.

Many of the questions that were asked in this interview were similar to the pre-interview questions. This allowed differences in knowledge before and after to be documented and measured. The interviews all began with asking the overall impressions and thoughts of the PrEP. This typically generated a positive response, followed by a comment on the length of the class. By asking similar questions to the pre-PrEP interview I was able to ascertain if the Explanatory Model of the participant had changed. I then would ask about their existing knowledge about their disease by asking them to recall symptoms, causation, and outcomes of their disease.

The question that generated the greatest amount of information was finding out the type of treatment they should receive. This enabled me to ask questions about the advantages/disadvantages that applied to them individually. This was a perfect time to observe the amount of information obtained and the application of that information. This would typically lead into why other forms of treatment would not work, allowing the discussion of barriers and limitations that were experienced.

The major limitation to this portion of the research design was the qualitative nature of the questions. This did allow me to obtain incredible information, however it made it difficult_to specifically focus on the relative effective of such individual factors as class or gender.

3.1.3 S-TOFHLA

The final portion of the research design included administering a health literacy assessment, the Shortened version of the Test of Functional Health Literacy (S-TOFHLA). I decided that it would be better to administer the S-TOFHLA after the interview process in order to remain objective. This allowed me the opportunity to observe the participants to see if I could determine the health literacy levels of the individual before administering the test. Since low health literacy is a silent disease and can cross boundaries of education, socioeconomic status, gender, and ethnicity, I wanted to experience finding out each person's health literacy level after involved interviewing had taken place.

The S-TOFHLA is one of the three accepted health literacy assessment tools that is accepted in the health care field. It was developed and validated through the Williams et al (1995) study "Inadequate functional health literacy among patients at two public hospitals." Through the use of actual hospital materials at multiple levels of reading difficulty (4th and 10th grade levels), participants answer 36 questions within a seven minute time frame. Their health literacy levels are determined through a ranking of correct responses resulting in inadequate (0-16), marginal (17-22), and adequate (23-36) levels. S-TOFHLA is the only assessment test that measures *functional* health literacy (Nurss et al 1995).

The measurement of health literacy enables the health care community to determine the level of understanding from the perspective of the individual. It presents a unique insight into the lives of the patients, helping those in the medical field understand why many chronic patients are unable to comply with treatment regimens and self-management skills. Diagnosing a person with limited health literacy is a complex process since it crosses boundaries and infiltrates every aspect of society.

3.2 Case Study

The following case study is an example of the impact low health literacy can have on a medical patient, specifically one with ESRD. The first individual is a male participant age 31 (Caucasian) who is highly educated and a self-motivated individual. He is a strong advocate for himself in seeking adequate health care. He is diabetic and has been 100% compliant with diet, exercise, and medication and has adequate health literacy. He is a good example of the type of individual that does everything in his power to achieve good health, but due to unprecedented circumstances, has been diagnosed with ESRD. Another male, age 49 (Native American) who is also diabetic is not compliant with diet, exercise, and treatment and has marginal health literacy. He has experienced extremely serious negative health consequences with his type II diabetes which has progressed to ESRD.

The difference between the two men is startling. The first had done an incredible amount of research in regards to his new diagnosis and knew all the terminology and has a very systematic plan for treatment. When asked, what does it mean to you to have ESRD, he replied, "It means it is time for a kidney transplant." In contrast the male, age 49, had little to no knowledge about his disease or treatment plan. When asked, what is your current kidney function level? He replied, "I don't know, but the doctor says that if things keep going like they are, I will have to start dialysis with in the year."

Although these two individuals are both male and are relatively young for starting dialysis (age 31 and 49 years), and even though they have completely different circumstances both have resulted in ESRD. However, the prognosis for the first male is much better than the second, because of his compliance and proactive attitude in his medical care. The real impact of low health literacy results in negative health outcomes and eventually death.

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CHAPTER 4: RESULTS AND DISCUSSION

The information received from interviews with 20 PrEP participants resulted in statistics and ethnographies, which has resulted in a greater understanding of ESRD and health literacy. Due to the complexities of treatment decisions and the required self-management skills, it is important to consider the impact of low health literacy on the individual. It is only together with statistics and ethnographies that a true perspective of the impact of ESRD and low health literacy can be obtained. The anthropological aspect of this research project is that it not only looks at the consequence of low health literacy quantitatively, but also allow the perspective of the individual to be understood through qualitative data.

4.1 Sample

Fieldwork for this study started in August 2005. Participants were obtained through a convenience sample with the goal of 100% participation rate of those invited to the PrEP offered at Samaritan Dialysis Services (SDS). The patient pool included individuals from Linn, Benton, Marion, and Lincoln counties in Oregon's mid-Willamette Valley and surrounding coastal area. Twenty-two individuals initially agreed to participate in this study. Two participants only completed the pre-interview; one did not attend the PrEP, and another was too ill to complete the post-interview. This resulted in a total population sample of 20 participants, 10 females and 10 males. During seven months of fieldwork, thirty-eight individuals completed the PrEP training, resulting in a participation rate of 53%.

CHARACTERISTICS	Health Literacy Levels			
	Total	Inadequate	Marginal	Adequate
Age (Mean)	69.25			
< 50	15%	0%	5%	10%
51-60	15%	5%	0%	10%
61-70	5%	0%	0%	5%
71-80	40%	15%	5%	20%
81 +	25%	10%	5%	10%
Gender				
Male	50%	20%	15%	15%
Female	50%	15%	0%	35%
Race				
Caucasian	85%	25%	10%	50%
Native American	10%	5%	5%	0%
Hispanic	5%	0%	0%	5%
Residence				
Rural	45%	20%	10%	15%
Urban	55%	15%	5%	35%
Level of Schooling				
High School	25%	10%	0%	15%
Some college	30%	10%	10%	10%
Bachelors	30%	10%	5%	15%
Post-bachelors	15%	0%	0%	15%
Marriage Status				
Married	45%	0%	5%	40%
Divorced	10%	10%	0%	0%
Widowed	30%	15%	5%	10%
Never Married	15%	5%	5%	5%
Kidney Function Level				
Unknown	20%	15%	5%	0%
10-15%	10%	0%	0%	10%
16-20%	40%	10%	5%	25%
21-26%	30%	5%	5%	20%
Symptoms				
Yes	50%	10%	10%	30%
No	50%	20%	5%	25%
Expectations for PrEP				
Yes	75%	10%	15%	50%
No	25%	20%	0%	5%
S-TOFHLA Score		30%	15%	55%

Table 2. Key Demographic and Socioeconomic Variables Observed

4.2 Demographic Profile

The demographic profile as portrayed in this study includes age, gender, race, residence location, marriage status and education level. The age of the participants ranged from 31 to 91 years old with the median age at 69.25 years (see **Table 2**). Fifteen percent of the population were 50 years or younger; 15% were between the ages of 51 and 60 years, and 5% of the population between the ages of 61 and 70 years (see **Figure 4**). The two largest groups were in the age categories of 71 to 80 years (40%) and 80 years or older (25%). Sixty-five percent of the PrEP population was over the age of 71, demonstrating the elderly age of ESRD patients.





There was little difference between the average age of male participants (67.7 years) as compared to female participants (69.1 years). However, it is significant to note that in the age category of 71-80 years, 25% were female and 15% were male. There was a shift in attendance for those 81 years and older, where 20% were male and only 5% were female (see Figure 5), showing that men were more likely to attend PrEP at an older age. This may be attributed to the way patients are referred to the class. The nephrologist only refers a patient when kidney function levels reach below 25%, or if there is a dramatic decrease in kidney
function levels. However, patients are also referred to the class if they express an increased interest in the disease process and available treatment options. Through interviews, I found this situation occurred only with women. For example, a 73-year-old woman with kidney function levels at 25% remarked that she was invited to PrEP because she took up so much time asking questions during her doctor appointments. When I interviewed her I spent over an hour talking to her about treatment options and other questions regarding the disease process just as she had for the doctor. Therefore, women may be attending PrEP earlier than men because of the increased expression of interest in their disease and available treatments.



Figure 5. Age and Gender of Participants

The population sample from the mid-Willamette Valley and surrounding coastal areas included 55% from an urban residence and 45% from a rural residence (see <u>Table 2</u>). Those from a rural residence expressed more self-reported barriers specifically in regards to access of medical treatment and transportation. Combined with residency location, 75% of the study participants owned their homes compared to 25%, which lived in rental properties (see <u>Table 2</u>). Rural residency and low socioeconomic status are both important characteristics in limited access to health care and an increased number of self-reported barriers.

The racial distribution of the participants were self-identified as follows: Caucasian 85%, Native Americans 10%, and Hispanic 5% (see <u>Table 2</u>). All participants that self-identified as Native American or Hispanic lived in a rural location compared to only 30% of Caucasian participants (see <u>Figure 6</u>). The combination of a minority status, low socioeconomic status and rural residency increased the risk of barriers preventing adequate health care. For example, this was seen in a 65-year-old Hispanic woman who rented a house in a remote location in the coastal mountains. Due to bad roads, cost of gas, lack of public transportation, increased driving time, and frequent power outages she felt it necessary to move to the city of the dialysis center in order to have better access to health care. However, she worried about the cost of rent in the larger city because of her limited income.





Social support for patients with ESRD is vital. A major source of social support comes from the spouse of the patient. Within this population, 45% of participants were currently married; 30%, widowed; 10% divorced; and 15% never married (see <u>Table 2</u>). For those without a spouse to provide the necessary help with medications, doctor appointments, and emotional support, some relied on friends, neighbors, or extended family. However, some were unable to obtain

anyone as a social resource. For example, a 91-year-old man who lived in a rural coastal town was widowed and had no family nearby. He was without support from neighbors or friends, but his family in an effort to give him the support and independence that he needed, purchased a social support for him. This was accomplished through his family hiring a husband-and-wife team that helped him in any capacity that he needed. For example, the wife cleaned and cooked for him, and the husband did needed repairs around the house as well as took him to doctor appointments. In fact after three months of attempting to attend the PrEP, it was only after the family hired this couple that he succeeded, because the husband brought him. This demonstrates how vital a social support is to someone diagnosed with ESRD. Dealing with ESRD is extremely difficult especially for those that do not have access to a social support system, and are incapable of purchasing one.

The participants in this study had a higher average education level that those documented in other health literacy studies where a large percentage (40%) were not high school graduates (Williams et al. 1998; Baker et al. 1999). This is seen when 25% received their high school diploma, and 30% continued on to complete some type of post-high school education such as a license or associate degree. Another 30% continued even further completing a bachelors degree and the remaining 15% received a masters, doctorate or attended a professional school (see Figure 7). Seventy-five percent had completed some type of post-high school education.



Figure 7. Highest Education Level Achieved by Participants

4.3 Demographic Comparison: PrEP and ESRD Population

The demographics of this population are comparable to those of the incident ESRD population as described in the Annual Data Report of the United States Renal Data System (ADR). Although the ADR does not collect all the same demographics as in this study, correlations can be made that demonstrate a relationship between the PrEP participants and the ESRD population in the United States. The median age of the PrEP participants was 67.7 years compared to 64.8 years of the ESRD population. <u>Table 3</u> shows the age categories of PrEP participants as compared to the national ESRD incident population. The PrEP participants were older than the general population with 65% being 70 years or older compared to 37% of the ESRD population (see <u>Table 3</u>).

The high median age of PrEP participants can be explained by the high percentage of participants above 81 years of age including one participant age 91, and three participants age 86. There were significantly more PrEP participants over the age of 70 as compared to the general ESRD population, and it is difficult to know if the increased percentage of the PrEP population within specific age category was typical of this area or an anomaly, because of the small population size.

Age Categories	PrEP Participants	ESRD Incident Population
< 49	15%	21%
50-59	15%	19%
60-61	5%	23%
70-79	40%	24%
80 +	25%	13%

Table 3. Age Categories of PrEP participants compared to ESRD incident population

(ADR 2005)

According to the ADR 2005, the incident ESRD population nationally has 54% males as compared with 46% females with a continued increase of males beginning treatment. Although the population of this study had half from each gender, this study did not document the beginning of treatment only the attendance of PrEP. Therefore, this population may follow the current trend as seen by the ADR with more men beginning treatment than women (ADR 2005). The increased trend of males beginning treatment may be explained by examining the attendance of women at an earlier age thus delaying the beginning of treatment. Another possible explanation could be explained through health literacy levels which will be discussed in a later section.

The racial/ethnic composition of the study population (see <u>Table 2</u>) as compared to the ADR population depicts a continued trend of Caucasians being the largest population of ESRD patients (75% and 66% respectively). However, the Native American population was represented by 10% of the sample size, which is much larger of a representation than the ADR findings of 1%. The Hispanic population was only represented by 5% in the PrEP sample compared 6.3% of the ADR report. According to the ADR 2005, the Hispanic and Native American population has been increasing in the recent years due to the increased prevalence of type II diabetes and hypertension among these populations (ADR 2005). This too may be a negative consequence of low health literacy which has a high prevalence among minorities. The remaining demographics (residence location, socioeconomic status, marriage status and education level), which were compiled for this study, were not collected by the ADR. However, they play an important role in treatment options and receiving care.

Patient residence can be a potential barrier to receiving care. For example, there is typically a dialysis clinic in most major cities throughout the United States, but not everyone lives near a major city. This is especially true in Oregon, because of the many areas that are rural. In the coastal regions of Oregon, populations are low, and there are a lack of Interstates that make large cities accessible. This results in some patients driving for 60 to 90 minutes in order to reach the nearest dialysis center, and when those dialysis patients are unable to drive and public transportation is unavailable, treatment is even more difficult to obtain.

Social support through family members, friends, and neighbors plays an important role in helping the patient to physically, emotionally, and socially deal with a disease such as ESRD. Those that had a strong, positive social support—especially through a spouse—reported an optimistic outlook on their prognosis.

The education level of PrEP participants is high, however the ADR does not collect education level of ESRD patients so comparisons cannot be made. It is assumed that the average education level of ESRD patients is typically lower than those the PrEP participants because of the comparisons to other health literacy studies and the higher per average high school graduates. It is assumed that this geographical area may have a higher education level as compared to other areas. Participants with lower education level experienced more barriers and frustrations.

4.4 Perceptions of Disease

The qualitative data gathered through the Explanatory Models of the participants provides a unique opportunity to determine emerging themes within different demographics. This allows the ethnographic material to be compared, through looking at themes within age categories, and health literacy levels in order to offer a greater understanding of the impact of ESRD. This is facilitated through understanding the perception of the disease (ESRD) through the perspective of the individual.

4.4.1 Explanatory Model

The Explanatory Model of the participants were collected initially during the Pre-PrEP interview. As seen in Appendix A, the first six questions consisted of demographic questions. The questions were not only important for research purposes, but they also allowed a flow of information between the participant and me, the researcher. This establishment of rapport was facilitated predominately through the participant discussing their employment, schooling, ethnicity, and family. These were all comfortable topics of discussion that engaged reflective thinking.

The following are three examples of explanatory models that were collected from participants. The focus of these case studies are to reveal the terminology of the participant, their understanding of the causation of ESRD, and what symptoms they are experiencing. The use of qualitative information also allows the researcher and medical staff gain an insight to the experience of the individual. It is through the use of the Explanatory Model that the individual impact of ESRD can be understood.

4.4.1.1 Case Study #1

The following is the explanatory model of a 72 year old Native American woman who had inadequate health literacy. She lived in a small camper trailer on the property that she won in her divorce settlement.

What do you call the illness that you are experience? I don't know what to call it. I had a stroke, and I had trouble controlling my bladder, and the diabetes made me urinate more, so...but I don't know that I could pinpoint what a name is for it.

What would you say has caused all your kidney problems? I blame it all on my ex-husband, no...the medication. In my process of going through a divorce my doctor later told me that he thought I was going to die. I was starving myself to death. I wasn't eating right. I think that caused a lot of problems. I lost about 40 pounds quickly. My eating didn't improve until my daughter took me home for the winter. She forced me to eat, and I had a granddaughter that drove me everywhere.

What are your health problems that you are dealing with? I am diabetic, my eyes, I have inherited blood pressure...that changed when I got divorced. He was a controller. For 48 years he told me what I could and could and couldn't do, and after he left my blood pressure was less of a problem. 'What about your kidneys?' Oh it fluctuates. For a time they were improving then it goes down. I didn't realize that one of the medications I was taking on affected my kidneys. If they had told me in the beginning that it would affect my kidneys I wouldn't have taken it. It was killing 'em and damaged them. I was on it for many years.

What symptoms have you experienced? I have not noticed any.

What levels are your kidneys at now? Oh, I don't know.

What are you hoping to learn from this class? Any thing they can tell me. Depends on how much I can remember. I will take notes. Re always learning and going to classes and stuff. I have learned the most from them

What type of treatment would you be interested in? The kind you do at home. I think anyone would. I've been in there where those people on them dialysis machines.

Do you have an worries about dialysis or your kidneys? Not after being around my friends and what he can do.

Has your doctor put you on any diet restrictions? That is why I am going to this meeting. Not yet. After I gained my appetite back, I gained all my weight back. It is hard to loose weight as a diabetic. I can't go walking anymore after my stroke, because now I have to use a cane. I miss being able to walk outside. It is clear from this case study that the participant had a good relationship with her nephrologist. He understood that her divorce was a difficult experience for her and acknowledged that it had an impact in her poor health. However, she had little understanding that it was the diabetes that caused the kidney damage. It is also obvious that there is some mental capacity problems that impair her level of understanding. It is a good example of the health barriers that are experienced by many dialysis patients.

4.4.1.2 Case Study #2

Case study two is from a 65 year old woman, who did not attend the PrEP. Despite her rapidly declining kidney function levels she did not attend the class nor future classes. Eventually she must have moved out of the area, because her phone number was no longer valid. It is possible that her family situation created a barrier that prevented her from attending the class. There were a lot of family problems that were creating a lot of stress.

What do you call the illness that you are experiencing? Diabetic, arthritis, and my kidneys are beginning to fail.

Tell me about the experience you have had in regards to your kidneys failing. There has been a lot of pain, whether it is from the kidneys or due to a lower back injury and arthritis I don't know. When I was a kid someone pushed me off of the bleachers and I hit the corner. I have a spinal injury...it crushed the last two vertebrae. From that it bothers my hip, but I also have neuropathy of the feet, which from what I understand the glucophage and the nurotin is what helped cause the kidney failure. I don't know if I damaged my kidneys when I fell off the bleachers because it was when I was 9 or 10. I have known I had kidney problems for about a year. The doctor has been monitoring them through lab results. He says that my kidney function levels are at 20-30%. I has been declining, and is the reason that I have been asked to go to this class.

Other than the pain in your back what other symptoms have you been experiencing? That is it.

What does it mean to you and your family to have your kidney's failing? I have no idea how this is going to affect me and my family.

What kind of treatment do you think you should receive? I have made no decision on the type of treatment that I will receive because I don't know anything yet.

What are the most important results you hope to receive from this treatment? I have no idea of how I will feel after I start receiving treatment.

What are the main problems that your kidneys failing has caused? I have to go to the bathroom more often. It is sometimes defeating especially if you have just already been there. I have to get up during the night to go. It effects my sleep too.

What do you worry most about your kidneys failing? I have never really given it much thought, because I don't really know what it all involves. I know that it strains your blood, but other than that I have no idea what it is.

What are your expectations of the Pre-renal class? Whatever they tell us.

What and where have you received your information about kidneys failing? I had a friend that was on dialysis but I never talked to him about it. I have no idea what type of dialysis he did. This was in California.

This woman is a good example of how little is understood about the causation and seriousness of the disease. She had done little to no research about her disease. It was surprising when she didn't attend the class, and it would be interesting to know why. Based on conversations with the PrEP coordinator, frequently patients don't attend PrEP after they initially agree to attend. The reason for this can be varied, but it was her opinion that there was some sense of denial involved. Her understanding of the causation of ESRD is similar to the previous case study, and these are not the only participants that stated that their medication was the cause of their ESRD.

4.4.1.3 Case Study # 3

Case study is from a 75 year old man who has many health problems, but is only agreeing to do dialysis because of his failing wife who has Alzheimer's.

What do you call the illness that your are experiencing? Kidney Failure. Tell me about the experience you have had in regards to your kidney failure. I have had eight surgeries on my left leg, five totals on that knee And now it is broken again. I can't have surgery because of my kidneys. The last two surgeries I went bonkers, and I didn't know my wife, I didn't the doctor. I thought they were going to kill me. They finally put me in a room with a ringer bell on my bed. Every time I got off my bed that ringer went off, and they came a running. That was real to me! As real as it can be. It went through three different scenarios while I was there. Then we move up a bit, and I have had prostate surgery. Then I have had rotator cuff surgery. Now it is completely separated. Then they found out that my other rotator cuff is broken in two places, and I need to have surgery for it as well. Then I had this done for dialysis [pointed to arm and the fistula], but it is not ready yet. I don't understand it at all. Surely they've got to have more area than that to stick all those needles in there.

My hearing is gone. I have had spinal meningitis. I think only two of us that lived out of the fifteen that had it. I couldn't even comb my hair because my headaches were so bad. The doctor couldn't speak a word of English.

My heart. I've had three stunts put in my heart. They just did a test not to long ago which I think made my kidneys go bad. They used that dye stuff, and now my kidneys are at 10%. He wants me on dialysis right away, but this [pointing to the fistula] isn't ready.

I have high blood pressure. If I am sitting or lying down in bed, if I stand up I get even very slowly I get extremely dizzy. What happens is my blood pressure goes from 132 to 78. I just stop! So the VA put me in a wheelchair. Now I don't have any arms or shoulders so I can 't work a wheelchair. So it puts a bind in everything. Now they found out that one of the stunts in my heart is plugged. So I need to have surgery in that.

I've been watching my kidney levels for 7-8 years.

What do you think has caused your kidney failure? It could be several things. When I first joined the service I spent the first few years on the islands. Yuogima, Guam, Tiepin, Bermuda and a couple of others. But on those islands they gave you salt tablets, and it wasn't a matter if you wanted them or not....they gave them to you anyway and you took them. We took tons of them. Of course you know what salt does to your kidneys. Then after that I think the main problem was medication. This is my feeling. Because I have had so many surgeries and so many pain pills. I mean it was getting to the point of oxycotin doesn't faze me. You talk about surgery, it scares me to death. Probably the only thing that would work is probably morphine. But that makes me sicker than a dog. I think that has a lot to do with it. Then they got me to where I was addicted to that. I went to a drug counselor within the veterans and then also....now I've got medication in there but I don't touch it because it messes up my system. I can't relieve myself, headaches, and blah. It has bee the bigger problem.

What information have your received about dialysis? I have been to a dialysis center in Bozeman Montana. I just walk through.

What concerns or worries do you have? My biggest worry about dialysis is doing dialysis. I know all lot of people who have done dialysis, but it is different when it is yourself. I will be honest. I don't want anything to do with dialysis, but I've got this situation [he points to his wife]. If I don't go through dialysis I'm gone and she is alone. That is the primary reason I am going to do dialysis, otherwise I would not do dialysis.

This man exemplifies how many of the patients with ESRD have multiple chronic illnesses. He has experienced many medical struggles, which are compounded by his desire to live because of his wife's condition. He expressed a lot of fear through out the interview, and also during the PrEP. This can be more fully understood by his past experience and inability to take pain medication. This is a good example of the type of insight that is gained through Explanatory Models.

4.4.2 Explanatory Model Findings

In the pre-PrEP interview, the first question I asked was in regards to their disease. "What do you call the illness that you are experiencing?" The response to that question resulted in 40% of the study participants who used informal terms to describe their condition. Twenty percent called it "problems with kidneys," 10% called it "pain in the butt," and 10% felt that their "kidneys were messed up." Thirty-five percent defined their illness as kidney failure; 5% defined it as ESRD, and the remaining 20% used "polycystic kidney disease" to identify their condition.

The use of informal terms allowed participants to verbalize the personal perspective they had on their disease. Even after attendance at PrEP, where formal terminology was presented, the use of informal terms did not change, nor did the way the participants defined their illness. For example, if a person described their illness as 'a pain in the butt' that term was still used after attending PrEP, however, they did report the PrEP training helped establish a better understanding of their disease. By comparing the participants use of informal to formal medical terminology it facilitates a greater insight into the understanding and perspective of the individual.

Respondents overwhelmingly felt they acquired more knowledge about ESRD by attending PrEP. For many of the participants, the understanding of their condition and the use of informal terms were reaffirmed through the information gained in the PrEP. For example, one respondent learned that the kidneys serve many functions, and the knowledge she received helped her overcome the guilt she had felt. She realized that even though she didn't manage her diabetes in the past, she could play an active role in her health care now and that would prevent further damage to her kidneys. She experienced an attitude change that was assisted through obtaining knowledge and skills at PrEP. She is now proactive in her responsibility of improving her health through diet, exercise, and medications. In order to determine their understanding of the causation of ESRD, I would ask, "What do you think has caused your illness?" The three most common causes of disease among the PrEP participants included type II diabetes, hypertension and Polycystic Kidney Disease (PKD). However, there was an extreme difference in the PrEP participants with PKD and the remaining participants. Even though all participants reported having experienced a chronic illness that could cause ESRD such as type II diabetes or hypertension, only those diagnosed with Polycystic Kidney Disease (PKD) had a good biomedical understanding of the cause of their disease. When I asked those with PKD what they would call their disease, they all responded with Polycystic Kidney Disease. Each of these individuals came from a variety of backgrounds, but they all had a clear understanding of the name of their disease (PKD) and the cause (genetics).

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Twenty-five percent attributed their condition to diabetes or hypertension and fifteen percent stated that prescription medication were the cause of their kidney failure. Another 25% saw infection, blockage, cancer treatment, or age as the cause of ESRD, and 15% stated they were unsure of the cause. There were other explanations that accompanied the biomedical causes such as stress, and excessive intake of salt. A lack of understanding of the disease cause and process prevents the application of information in order to prevent serious negative consequences. For example, those that don't understand that their blood pressure is the cause for their ESRD, they will not recognize the importance of taking their blood pressure medication to prevent future damage to the kidneys.

So many patients are diagnosed with ESRD because of their diabetes, hypertension or other chronic conditions. This not only compounds the complexity of the disease, it is not unique to this PrEP population. Based on the ADR most ESRD patients carry five or more comorbid conditions when they begin treatment (ADR 2005). The complicated nature of ESRD combined with up to five chronic illnesses can place an insurmountable amount of requirements on an individual. As I entered the homes of so many PrEP participants, I saw the amount of medications each was required to maintain their current quality of life. I observed the astronomical costs involved in the medications and how the routine of taking those medications consumed the day of the individual. I also saw the calendars and day planners of the PrEP participants and realized the complexity of scheduling appointments with several different specialists and primary physicians. For many the scheduling, planning and medications is an overwhelming process that requires many participants to rely on others for support.

Through asking "what do you think this illness does to your body" I was able to establish that 50% of study participants experienced common symptoms of ESRD such as extreme fatigue, loss of appetite, being cold, edema, and leg cramps. Thirty percent of participants did not report having any symptoms of ESRD, and 20% did not know what symptoms were associated to their disease. Multiple chronic illnesses may be an explanation of why 20% didn't identify any symptoms of ESRD. It is a possibility that they are already in so much pain and experiencing so many symptoms, it is difficult to distinguish which ones are from their kidney disease. A 91-year-old man stated that for him all symptoms for all diseases are the same and "when you feel lousy you feel lousy." He was experiencing so many complications from his diabetes, he was unsure of what was causing him to feel poorly. However, it is important for patients to know the symptoms associated with ESRD because it can indicate serious complications which can be life threatening.

Many participants were surprised to learn some of the symptoms associated with ESRD and even though they had been experiencing them, they had not realized it was due to their ESRD. One woman had stated in her pre-PrEP interview that she wasn't experiencing any symptoms, but fatigue. However, during the PrEP she was so cold that I got her a blanket to wrap up in. During the post-interview, she said that from the class she realized that being cold was a symptom, but she also understood why her skin was so itchy. She thought that she

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had dry skin, not that her phosphorus levels were elevated. She was able to add a phosphate binder to her medications that eliminated that symptom.

Listening to the use of terminology by the participants, gaining an understanding of their explanation of the causation of disease, and examining their understanding of the potential symptoms associated to the disease are all ways to obtain the Explanatory Model of the participant. It is believed that the deeper understanding of the participant results in better communication between the physician/dialysis staff and patient causing the patient to become more involved in the treatment option and increase compliance with those patients that are feeling frustrated due to lack of understanding. This frustration was seen in a 75 year old man after he started dialysis. He stated,

"I don't see the team. Successful treatment of a disease this serious would have to include both parties. That means that they need to tell me some things. There not telling me a cotton-pickin thing. Nothing! Zilch! There not telling me what my blood test results are, my phosphorus or salt, or anything. Well, how do they expect me to work with them especially in regards to food if I don't know where I'm at! I can't get anyone to talk to me. I asked them about the machines and they said, 'Well, there's really nothing there you need to know.' If I don't know about it and what it is doing then...they explain a little about it, but I want to know what's happening to me. It just gives me the impression that they don't care." Male Participant (75 yrs.)

This frustration is to be expected after beginning a life altering treatment and not fully understanding the ramifications involved. This individual had attended PrEP, and had received a lot of information about his disease and the treatment. This interview took place a week after starting dialysis and having to be transported by ambulance to the hospital after a treatment. Perhaps if the dialysis staff would have understood his situation better (see Case study #3) and realized that he truly wanted to understand it is possible that he could have had a more positive experience. On the other hand I can only imagine the experience he would have had without the exposure through PrEP.

4.4.3 Explanatory Model Themes

One of the advantages to utilizing the ethnographic method of explanatory models is that specific themes can be seen throughout the sample and within sample subgroups. Being able to compare emergent themes within subgroups gives the ethnographic information its validity. Patient's age and health literacy level emerged as two important subgroups in the present study. This information of emergent themes will allow the dialysis staff and physicians to utilize certain demographic characteristics as an indicator to certain issues and barriers that may be experienced by specific groups. For example knowing that many of the rural patients have a concern with transportation, it can specifically be addressed for all rural patients.

A main theme that was presented throughout most interviews was the overwhelming feeling that consumed ESRD patients. There is so much information that is required of them to understand, and it seems insurmountable to many. Some of the participants reacted with a denial of, "I have not given it much thought. I have made no decision on the type of treatment that I will receive because I don't know anything yet." Others reacted in the complete opposite realm of learning everything there was to learn about kidney failure and dialysis. This theme was consistent with health literacy levels. Those with more exposure to their disease through personal study appeared to have a better understanding of their disease and were able to have a better attitude about their prognosis. Those with adequate health literacy were the only ones that had done personal research about their disease. There were those that had adequate health literacy and had first hand exposure such as a family member, or friend and they too were able to deal with their diagnosis the same as those who had done extensive research. However, there were not any of the participants with inadequate health literacy that were able to be proactive in researching and resulted in them feeling overwhelmed by their disease.

Each age group presented different obstacles in regards to being diagnosed with ESRD. The younger PrEP participants felt cheated out of their life with the

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diagnosis. One 31-year-old male was engaged to be married, but his fiancée left him because of his diagnosis, and he has found it difficult to continue working with the extreme fatigue that comes with ESRD. For the middle-aged participants, retirement meant traveling and activity, but dialysis requires a person to remain close to home. Individuals who were diagnosed with ESRD at an older age, specifically 80 years or older, the issue of sustaining life through treatment such as dialysis made many examine the decrease in their quality of life. Some decided that the life-extension provided by dialysis wouldn't be worth the personal cost. For those that were widowed and had several health problems, dialysis was not an option that appealed to them. However, those that had a spouse in need of their support, even if their quality of life would decrease dramatically would choose to use dialysis to sustain their life.

The most ominous theme was the topic of death. Fifty percent of the participants talked about death, and some of them felt that the diagnosis of ESRD was a death sentence. Many were getting their things in order, because they don't want it to be burdensome to their children. One man stated that when he was being diagnosed that "...all of the sudden they found out the blood wasn't registering like a normal person's blood, more like a person that had bled to death." By having the diagnosis of ESRD he was no long a 'normal person' and that dialysis might "...give me a chance at life for a brief time at least." Two patients over the age of 86 decided that their quality of life would decline drastically making the emotional cost of dialysis not worth it. Both had serious health problems, and realized this was their opportunity to be done with all the pain in their lives.

It is through applying the concepts from the emerging themes seen in these subgroups that potential barriers can be prevented, and a greater understanding between the dialysis staff/physicians and the patient can be achieved.

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4.5 Expectations, Treatment Option, and Barriers

Expectations of PrEP included participants expressing an interest in learning more about the functions of the kidney, treatment options, diet management, or meeting others with ESRD. A majority of the respondents (75%) had specific expectations about the PrEP. They felt that the PrEP would educate them about their "kidney problems." However, some respondents felt that they did not have any expectations because they had no prior information about ESRD or the treatment options available to them. Those that had done prior research about ESRD and treatment options had a better understanding of what would be offered in the class and were able to gain more than basic information about ESRD.

The primary purpose of PrEP is to inform participants about the treatment options that are available so that they can make an appropriate decision based on their lifestyle and individual situation. Some participants had little knowledge about their disease before attending the class; however, all but 10% were able to make a preliminary decision on the type of treatment that they would choose. Fifty percent stated that hemodialysis would be the best choice for them; 15% were interested in peritoneal dialysis, and 20% felt that they would like to do a transplant as a treatment option.

After attending PrEP, a majority (75%) of study participants chose hemodialysis as the primary form of treatment; none chose peritoneal dialysis; 15% wanted to proceed with a transplant, and 10% didn't want to do any treatment. There was a huge shift in participants who had thought about peritoneal dialysis but changed to hemodialysis as their primary treatment option. I had several comments similar to "I thought the home dialysis was simple, but it's not, it's a lot of work."

Sixty percent of participants expressed barriers to obtaining a certain treatment. Barriers that prevented people from choosing peritoneal dialysis included potential power outages, space for supplies, creating a sterile environment, arthritic hands, confusion, and sense of being overwhelmed. Worries experienced by participants choosing hemodialysis include transportation, traveling, fistula, needles, time commitment, and lack of a care provider in the family. Although for most, hemodialysis is the only option or last option available to them, many of the barriers were the result of fear, frustration, and depression.

A good example of a participant changing from peritoneal dialysis to hemodialysis was a 73-year-old woman who would have been a good candidate for peritoneal dialysis. She was relatively young with overall good health and was very knowledgeable about the treatment options available to her. She initially was interested in PD, but after hearing the potential risks with peritonitis and the need for a sterile environment felt insecure with her decision. By the end of PrEP she had changed her mind to doing hemodialysis.

It was surprising to see all the participants interested in PD change their primary treatment option to hemodialysis. Based on the Health Belief Model, the perceived barriers (peritonitis, time commitment, storage space, and responsibility) outweighed the perceived benefits (convenience of staying home, ability to travel, and advantages to dialyzing daily). It may also be due to the increased exposure participants had to hemodialysis, especially the tour and opportunity to see and talk to actual hemodialysis patients. In the PrEP there was definitely more time spent on hemodialysis (tour) as compared to peritoneal dialysis, which could create an imbalance of self-efficacy building. It is possible that once the participants have more time to consider the options, do more reading and talk with their nephrologist and the dialysis staff, their decision may change. The important thing to note is that the efficacy to make the choice for peritoneal dialysis is available.

It is unusual that so many of the participants declined the treatment option of peritoneal dialysis. It has been documented that attendance in a pre-ESRD education class potentially increases the use of a home dialysis (peritoneal dialysis), results in an earlier evaluation for transplantation and increases the rates for preemptive transplantation (Mehrotra et al. 2005). Preemptive transplantation is when transplantation occurs before the need for maintenance dialysis takes place, which results in the greatest longevity and the highest quality of life. These consequences, as seen from pre-ESRD education, improves patient outcomes and significantly save Medicare money because hemodialysis is the most expensive form of treatment for ESRD patients (Mehrotra et al. 2005). Despite the results on PrEP participants, Samaritan Dialysis Services provides 27% of their patient population with peritoneal dialysis, which is one of the largest PD centers in the Northwest. This may be attributed to PrEP being offered at SDS and the ability of patients to change modality of treatment even after beginning hemodialysis.

The diet/nutrition portion of the class was one area that many participants were eager to hear because they wanted to learn appropriate skills and information of what they could do at home to delay dialysis and protect their kidneys. Although many of the participants were currently on food restrictions (75%) because of diabetes or hypertension, a majority of them did not comply with their current diet. Much of this was due to the lack of social support from family members or friends. Food restrictions affect the entire family as well as the participant's lifestyle. However, many felt frustrated and confused after attending PrEP. Fifty-five percent of participants came away with negative comments about the class . Only 20% associated the diet portion with giving them a motivation to change their negative behavior.

Overall there was a sense of satisfaction and elimination of fear once the participants had attended PrEP and were able to gain more knowledge about ESRD and the treatment options available to them. This demonstrates how vital ESRD patients need an educational program such as PrEP. It is through the attendance of PrEP that participants were exposed to information and resources. However, the presence of frustration experienced by participants even after attending the class suggests that improvements still need to be made.

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4.6 Health literacy

An important aspect of this research project was to measure the health literacy levels of the participants and determine their ability to understand information about their disease based on their level of health literacy.

4.6.1 S-TOFHLA

There are three major health literacy assessment tools accepted in the health care field, WRAT-R (Wide Range Achievement Test-Revised), REALM (Rapid Estimate of Adult Literacy in Medicine), and TOFHLA (Test of Functional Health Literacy). WRAT-R simply measures word recognition based on the assumption that if a person is able to pronounce a word, then they also understand the meaning. It is able to determine the reading grade level of an individual, but not determine their functional health literacy level. REALM is a similar test, measuring word recognition. Neither test is valid in Spanish nor do they test for the ability to read and understand numeracy (Parker et al. 1995; Nurss et al. 1995).

Ruth Parker and her associates developed TOFHLA in English and Spanish as a valid, reliable instrument that would measure the functional health literacy of patients and further explore the impact of low health literacy on health care. Not only is it the first test to measure health literacy in two languages, but it is also the first assessment of *functional* health literacy and numeracy skills. TOFHLA was compared to the findings of WRAT-R and REALM, two tests that were already established and accepted in the health care community. Correlations of TOFHLA with the REALM and WRAT-R were 0.84 and 0.74 respectively (p<0.001 by Spearman's rank correlation). The findings resulted in the TOFHLA being a valid, reliable indicator of the ability of a patient to read and understand health related materials (Baker et al. 1999; Parker et al. 1995).

The test was developed using actual hospital materials and consists of a 50item reading comprehension and a 17-item numerical ability test. The full test takes 22 minutes to administer. The development of the test resulted from more than 30 examples of common medical texts, including patient education materials, instructions for diagnostic tests, prescription bottle labels and instructions, and patient registration forms. From these, different texts samples were taken that demonstrated a variety of difficulty levels (Baker et al. 1999; Nurss et al. 1995).

The reading comprehension test utilizes the Cloze procedure, by omitting every fifth to seventh word in a passage. The reader is to choose from four possible solutions, three of which are similar but grammatically or contextually wrong (Parker et al. 1995). Three passages are from: (1) instruction for preparation for an upper GI series (readability grade level 4.3), (2) a Medicaid patients rights and responsibilities (grade level 10.4), and (3) hospital informed consent agreement (grade level 19.5) (Nurss et al. 1995). The numeracy portion consists of a 17-item test that requires the patient to comprehend directions for taking medications, monitoring blood glucose, keeping clinic appointments, and obtaining financial assistance with a weighted average readability at grade 9.4 (Baker et al. 1999; Nurss et al. 1995).

The validity of the test is based on an initial pilot study of a convenience sample of 200 English-speaking patients and 203 Spanish-speaking patients both in a clinical setting. The design of TOFHLA is primarily used in a research setting, due to the length of the test (Parker et al. 1995). The first study that addressed the issue of functional health literacy using the TOFHLA was the groundbreaking project by Williams et al. "Inadequate functional health literacy among patients at two public hospitals" (1995). The goal of this study was to measure the prevalence of limited health literacy in the general population. This was the first published study to assess the ability of patients to perform the wide range of literacy tasks, such as comprehension and numeracy, needed to function in the health care environment. The findings of this monumental study indicated a high prevalence of inadequate functional health literacy, which is consistent with the NALS of 46-51% of adults with deficient literacy skills (Williams et al. 1995).

After the validity of the TOFHLA had been established it was necessary to develop an abbreviated form of TOFHLA to be used in a clinical setting. In

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response to this need, the development S-TOFHLA resulted (see Appendix B), which can be administered in 7 minutes. It consists of 36 reading comprehension items: preparation for an upper gastrointestinal series (4th grade level) and the patient's rights and responsibilities section of a Medicaid application (10th grade level). The participants' literacy levels are determined through a quantitative method by administering the S-TOFHLA, which ranks them with scores placing them in the categories of inadequate 0-16, marginal 17-22, and adequate 23-36 health literacy levels (Nurss et al. 1995).

The initial study of S-TOFHLA consisted of a 211 patients with a reliability of 0.97 (Cronbach's alpha) and a correlation with the REALM of 0.81 (Nurss et al. 1995). This study found that 34% had inadequate, 12% were marginal, and 54% had adequate health literacy levels (Baker et al. 1999). The reliability and validity of the S-TOFHLA were similar to the TOFHLA, but it is found to be more practical because of the minimal time needed to administer, and the scoring is less subjective. The S-TOFHLA is the shortest instrument available that still provides a complete assessment of functional health literacy (Baker et al. 1999). The largest population survey compiled on health literacy (Paasche-Orlow et al. 2004) indicates that 46% of the U.S. population have health literacy levels that are below adequate (Paasche-Orlow et al. 2004).

4.6.2 S-TOFHLA Scores of PrEP Participants

Through the use of the S-TOFHLA, I was able to assess the health literacy level of the participants. Thirty percent had inadequate health literacy levels; 15% had marginal health literacy levels, and 55% had adequate health literacy levels (see **Figure 8**).



Figure 8. S-TOFHLA Level of Participants

It was shocking to comprehend that 45% had limited health literacy (inadequate and marginal) when 75% of the total population had completed some type of post-high school education. An example of a high education and low health literacy was seen in a 57-year-old woman participant with a bachelors degree. Her kidney function levels were at 17% when she attended the class, and she had multiple health problems, including diabetes, carpal tunnel, congestive heart failure, and obesity. In her explanatory model of ESRD, she stated that she had experienced chronic urinary tract infections that had gone untreated for possibly several years and escalated to the point that caused her kidneys to fail. It was at that point that I realized the impact low health literacy had on a person's health care field despite her multiple chronic conditions. She had failed to learn how to navigate the health care system and advocate for herself to prevent an infection from destroying her kidneys. This demonstrates how low health literacy crosses boundaries and affects even the well-educated.

There were many who were very skilled at keeping their health literacy a secret, and there were others who used obvious techniques to avoid certain situations. This was seen after the first two interviews of the study, when I administered the S-TOFHLA. I was surprised to discover that despite the overall

understanding of their medical condition, one had inadequate health literacy and the other had marginal health literacy. Once I realized their health literacy levels, I went back and looked at my notes from the interviews. I saw words like "fatal, death, older." There was a sense of acceptance and preparation for death. There was a dependence upon others, physicians and children to make decisions, and remember things for them.

From the experience of the first two interviews, I realized how people can go through their medical experiences and develop coping mechanisms to hide, even from themselves, the reality of how little they understand medically. I was then able to recognize many of the coping mechanisms coping mechanisms used by participants and the impact low health literacy had on their health. For example, one woman was taking the reading comprehension portion that dealt with Medicaid Rights and Responsibilities that is at a 10th grade reading level. It was obvious that it was very difficult for her to understand. She finally responded that, "I don't do anything with *Medicare*, my daughter does it all." She refused to answer the questions. Another man, when asked a question, "what did you learn in the section about diet," would respond with a very general overarching comment, such as, "I learned everything I needed to." However, when pressed for specific examples he was unable to give them, indicating a very low level of understanding.

The largest population survey compiled on health literacy (Paasche-Orlow et al. 2004) indicates that 46% of the U.S. population have health literacy levels that are below adequate. The S-TOFHLA scores of the PrEP participants indicated that 45% have health literacy levels that are below adequate (see <u>Table 3</u>). Although the percentages are comparable, there is an increased percentage of inadequate health literacy among this population. This could potentially increase the negative consequences because of the complicated nature of ESRD and treatment regimen required.

Health literacy level	Paasche-Orlow et al. study	PrEP (pre-dialysis population)
Inadequate	26%	30%
Marginal	20%	15%
Adequate	54%	55%

Table 4. Comparison of Health Literacy Levels of Paasche-Orlow et al. study and PrEP Participants

(Paasche-Orlow et al. 2005)

In this study, characteristics of those with low health literacy included the following: males, minorities, participants that lived in rural areas and those that expressed no expectations for PrEP. Among other negative consequences of low health literacy is a lack of understanding of their disease which creates a sense of "fear of the unknown" and many feel that a diagnosis of ESRD is "a death sentence." The effect of this is that a majority of the participants before attending PrEP express a realization that death is inevitable. For example, I asked an 85-year-old male with marginal health literacy what he hoped to gain from treatment after being diagnosed with Polycystic Kidney Disease, and he stated:

[I hope] to prolong my life as long as possible. There is no way to prevent this from happening because once it starts working it is a cryptic disease that just keeps going and going till.... However, if you are aware you have it, you can be aware of the changes, and could probably forestall it off for years. But you can't avoid it. It is like riding a bus over a cliff, eventually you're going to hit the bottom. The main thing is to have a purpose in life and take it as it comes.

Male Participant (85 yrs)

There is a sense of fatalism among those patients with low health literacy, and poor social support. Although his fatalistic attitude decreased after he received information through PrEP and was able to have a better attitude about his future, because of he better understood the process and this empowered him to be able to have some sense of control over his situation. This was seen during the post interview when he stated, "I hope to get back to 70-80% of normalcy, I think I would be very happy. I might be able to extend my life to enough years so that I ca get my stuff all taken care of." Understanding the statistics of the prevalence of low health literacy is only one perspective. It is when there is a person behind the meaning of those numbers that the impact of health literacy is understood. However, the prevalence of low health literacy of ESRD patients before treatment has never been documented. As a pressing social issue that requires an approach that is pragmatic, it is imperative to recognize demographics and characteristics that are associated with low health literacy among ESRD patients.

As seen in **Figure 9**, 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 residence. Twenty-seven percent of urban participants had inadequate health literacy as 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. According to this population, there is a strong correlation between residence location (urban vs. rural) and one's health literacy level.



Figure 9. Health Literacy Levels Based on Residence of Participants

Figure 10 compares health literacy levels and self-reported racial composition. Fifty percent of all participants with adequate health literacy were self-reported Caucasians and 5% were Hispanic. Participants with marginal health literacy included 10% Caucasian and 5% Native American. Those with inadequate

health literacy included 25% of Caucasian participants and 5% of Native Americans. Due to the small population size it is unclear if there is a strong correlation between race and health literacy levels, but findings indicate that more research could reveal a possible significance between race and health literacy.



Figure 10. Health Literacy Levels Based on the Race of Participants

Health literacy levels based on expectations of PrEP (see **Figure 11**) show that those with adequate health literacy levels, 50% of participants had an understanding of the purpose of the class as compared to 5% that had no expressed expectations. Marginal health literacy participants included 15% with expectations, and those with inadequate health literacy 10% had expectations and 20% did not. Expectation levels of PrEP are a good indicator of low health literacy and exposure to ESRD information prior to PrEP. This is seen when a majority of those with no expectations had inadequate health literacy.



Figure 11. Health Literacy Levels and Participants Expectations of PrEP

The comparison of gender and health literacy of the whole sample found that 35% women and 15% men were in the category of adequate health literacy (see **Figure 12**). Fifteen percent of men tested into the marginal health literacy level, 20% of men and 15% of the women had inadequate health literacy. Overall 35% of the men in the study had limited literacy skills as compared to only 15% of women.

Figure 12. Health Literacy Levels and Gender of Participants



In order to aid those offering PrEP, the use of four characteristics (residency, race, expectations, and gender), can aid in understanding the prevalence of low health literacy and the impact it can have on ESRD patients. The purpose of determining the prevalence of limited health literacy among populations such as the PrEP participants is to assist them in obtaining information in a format that is understandable and applicable to their situation. For example, if a person with inadequate health literacy has a history of non-compliance, a simple conversation would determine the patient's level of understanding of ESRD. After determining the level of understanding and establishing which areas need more explanation, one on one instruction could take place. The use of pictures and visual aids could facilitate a better understanding for those individuals.

4.7 Program Evaluation of PrEP

The program evaluation of the Pre-renal Education Program is fulfilling the Objective 11-3 of Healthy People 2010, which is to increase the number of health communication activities that have been evaluated as successful interventions (HHS 2000). Through the evaluation of this program a determination of an effective health education program can be made. The primary criteria for evaluating PrEP is whether or not participants are able to make an appropriate health related decision after attending the class, regardless of health literacy levels.

The impact of PrEP is positive, in the sense that all participants are able to gain information regardless of their health literacy level. Those with higher health literacy levels are able to gain more information from PrEP; however, even those with limited health literacy levels are able to gain enough information in order to make an treatment decision that they feel comfortable with. This was seen specifically with a 91 year-old gentleman who had inadequate health literacy, and determined after a cost-benefit analysis that his quality of life through treatment would decline drastically. He stated after attending the class, "…it enabled me to make a decision." He then calculated some numbers for me describing the amount

of time it would consume. "It would take two hours over, four hours there, and two hours back, by then the day is shot three times a week and then your week is shot." This cost-analysis continued, "Are you willing to give half a week just to last another day? I am not!" It was obvious that he was content with his decision to do 'no treatment.' That is the purpose of this class.

Many times patients diagnosed with a serious chronic illness such as ESRD posses characteristics and demographics that place them in a high-risk category of being unable to navigate the complicated health care system. According to Healthy People 2010, "often people with the greatest health burdens have the least access to information, communication technologies, health care, and supporting services (HHS 2000)." Although this patient exhibited many of those high-risk characteristics, through PrEP he was able to attain a level of_understanding that allowed him to make a decision he felt comfortable with.

The success of health education is based on the use of an outcome evaluation, which is used to measure short-term results described by the immediate effects of the class on the individual. Examples of the results include increased knowledge, attitude changes, expressed intensions, and behavior shifts (Wurzback 2002). The success of the PrEP is measured through the ability of the participants to appropriately apply the information received and choose a treatment option that best fits their lifestyle. It is the purpose of the program evaluation to determine the success of this education program. In the past there has been positive feedback from the individuals that have taken the course and the physicians who have increased the number of patient referrals to PrEP.

This positive feeling about the class was documented through asking specific questions about the PrEP. The questions during the post-PrEP interview included, "What did you think about the PrEP?" "Did it meet the expectations you had before the class started?" One response included:

It was wonderful. It answered so many questions that I had. Like I told you before, I was taking up all of the doctor's time just asking questions, and that is why he suggested that I go to the class. For example, I didn't know if I would still be able to urinate when my kidneys completely stopped functioning. I didn't know if I would be able to continue drinking liquid. I also learned I would have to be careful with the food that contains a lot of liquid. It makes me want to follow the doctor's instructions more carefully. I hope I will never have to go on dialysis. But now I know what to expect if I do.

Woman Participant (73 yrs.)

This was typical of many participants, that attended PrEP with some level of expectations. However, even those with no expectations came away with a great deal of information, and an overall sense of understanding of what the future holds for them.

This positive response of PrEP was received from all participants; however, the verbal and visual information varied individually depending upon the level of understanding or their health literacy level. For one man, the class had a huge impact on him, mainly by "seeing all those people on beds....20 some odd people, that really shook me up." Another participant, who was very educated about his disease, said, "You can do all the reading in the world, but hearing someone saying something, it [just] means more." His parents attended PrEP with him and were able to finally understand that there is no cure for ESRD, only treatments.

During my interviews, I learned that ESRD patients with low health literacy levels generally felt dependent upon others, such as physicians and children, to make decisions and to remember things for them. However, they were able to make a treatment option that they felt comfortable with, and they felt motivated to change behavior. This was seen specifically with a 79-year-old woman, who used her two daughters extensively to make medical decisions, and assist her in scheduling appointments. The only way that she remembered anything was through the use of a notebook where she would write down everything. In her interviews she referred to her notebook several times in order to tell me things such as her kidney function level and when she last saw her nephrologist. Finally, despite individual experience with ESRD, respondents in general expressed a strong feeling of frustration and depression. This general theme is important for researchers to recognize, that each individual experience is valid and unique. Understanding the impact of limited health literacy on the lives of ESRD patients allows a context-specific understanding that will help in better planning of education and intervention efforts. For example allowing the patients to express their illness stories of the individuals to be expressed, the patients will interpret by the patients as a dialysis staff that is compassionate and will This can be accomplished through the implementation of the recommendation, a greater impact of PrEP can take place.

4.8 Critical Medical Anthropology

There has been a call for anthropology to become more engaged in the academic and public arena with a greater focus on pressing social issues with a pragmatic approach (Rylko-Bauer et al. 2006). Critical medical anthropology requires looking beyond the ivory tower and utilizing praxis and application as a fundamental point. By addressing the health literacy level of pre-ESRD patients who are participating in an educational course, I am creating an awareness to a serious social problem and looking at those structures that cause and create it. This research project has been a focus on the ethnographic descriptions of patients suffering from ESRD and has created a better understanding of the impact of ESRD and low health literacy.

This project has been about policy, research and action. It began by seeing the perspective of the suffering individual and helping others to realize that they are suffering. Current research of low health literacy reveals the epidemic proportions that are affecting the U.S. population. PrEP is an intervention that is taking the information of individual suffering, the knowledge of low health literacy and providing a service to limit possible negative health outcomes.

CHAPTER 5: RECOMMENDATIONS

PrEP has been a successful intervention program that has been able to reach a population that would typically be unable to cope with a serious medical condition and the decisions required of them. Despite the low health literacy levels of the PrEP participants, they have been able to make a decision about a treatment option with the current presentation of information.

The recommendations based on the program evaluation of the Pre-renal Education Program are with the intent to improve the education course. Each suggestion is specifically designed with the understanding that 45% of PrEP participants have limited health literacy. As such, medical information should be presented in a format that is easy to understand and should utilize a variety of education and learning techniques. Through my observations and interviews with PrEP participants, I discovered that despite their limited health literacy levels, all participants were able to choose a treatment option. However, without the input of the dialysis staff and nephrologists, it is impossible to know for a certainty that the treatment option decided upon by each participant is the best choice. Nevertheless, all participants felt comfortable with their treatment decision based on the information received at PrEP.

Even though the information was presented in a format that enabled decisions about treatment options, I observed that participants experienced many other barriers and frustrations that could be eliminated. By applying the following recommendations many of the barriers and frustrations of the participants could be eliminated which would result in a more successful program.

5.1 Goals

The PrEP is a unique opportunity for the dialysis staff to have a personal experience with many of their future dialysis patients. This opportunity should be used to not only educate future patients, but to also inform them of expectations

and requirements of dialysis patients. The dialysis staff is a team that works together in order to improve the lives of those receiving treatment, and it is only together that this success can be accomplished.

As stated by the program coordinator, the overarching goals of PrEP are to educate participants to make appropriate treatment options and to prepare them for the future through emotional adjustment and planning. However, the goals and objectives of PrEP were not always transmitted to all the participants, indicating there is a lack of communication between the PrEP staff, nephrologists and participants. This can be seen when 25% of participants did not have any expectations of what would be learned in PrEP. These participants were more likely to have low health literacy and in the post-interview, they were more likely to have missed the benefits of PrEP that go beyond making a treatment decision, such as understanding and applying diet restrictions. Therefore, special consideration for that population needs to take place to ensure that they do understand the purpose of PrEP and what is expected of them after the course.

Although the PrEP coordinator identified the goals of the education course during an interview, it is unclear if all presenters had the same goals. By the PrEP staff agreeing upon specific goals that are stated in a reading level that is easy to understand by all participants, the expectations of the participants will increase. This will ensure that all participants are better prepared for the information they will receive. After attending the class, the stated goals will solidify in the minds of the participants what they should have learned and help them understand their specific role as a dialysis patient.

From my perspective as an observer, the dialysis staff does not appear to be unified as a team. Once the dialysis staff has agreed upon the overarching goals of PrEP, they need to determine specific short-and long-term goals, and the ways that those goals can be met through the presented material. It is important to ensure that those goals also appear in the material that is taken home and any other material that is used to publicize the program. After the establishment of the short and long-

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term goals have been made, a regular evaluation among the dialysis team needs to take place. This may be accomplished by the presenters taking the time to observe each other's presentations and evaluate each other, and to have a staff meeting where together they could discuss the needs of the participants. This does require precious time on the part of the staff, but it will ensure greater success and make PrEP more effective.

5.2 Explanatory Model

The phone call by the PrEP coordinator to invite patients to PrEP is a unique opportunity to gain important information about the individual. By doing a pre-PrEP Explanatory Model interview before the participants attend PrEP, it will save time during the class, help the participants have a positive experience and allow smooth transitions between presenters. This information could be written up in an easy to fill out form (see Appendix C) and given to all the presenters before the class. With a little preparation, significant time could be saved in the classroom. By using the Explanatory Model, the dialysis staff could collect some essential information that would enable them to prepare for the needs of each PrEP participant. The interview would include questions such as the following:

- What do you call the illness that has caused you to be invited to this class?
- What is your kidney functioning level?
- What is the cause of this illness?
- What do you hope to learn (expectations) from this class?
- Do you know what type of treatment you would like to receive?
- Are you on any special diet?
- If so, what do you avoid?
- Is there anything specific you would like to learn from the dietician?
- What insurance do you have?

It has been established that the prevalence of low health literacy is high among the ESRD population. However, there are time constraints that prevent the use of the S-TOFHLA to determine health literacy levels of each individual. Therefore, the use of the Explanatory Model questions could be an alternative to the S-TOFHLA. By asking these simple questions, red flags can be seen that will help the dialysis staff know if special attention will need to be given to an individual. Those individuals that are unaware of their kidney function level, have no expectations for PrEP, and have non-biomedical explanations to the cause of their kidney failure are more likely to need special attention. The dialysis staff has the added benefit of the medical information that I did not have access to, the medical charts of the patients. This information is available to the PrEP coordinator when participants are referred to the education class. From the diagnosis code and information from the nephrologist, a comparison to the cause of illness and kidney function level can be made and verified to see if it is reported accurately by the patient. This too will indicate the health literacy level and basic understanding of the current health condition of the individual.

The other questions asked during an over-the-phone Pre-PrEP interview will save valuable time during the class. For example, knowing the type of treatment that is of interest to the participant will allow the presenters to spend less time on other areas such as transplantation or no treatment options. On the other hand, if there is an extreme interest in peritoneal dialysis, for example, the presenter would be able to focus on that topic for certain individuals. This will also allow the presenters to know the participants in the class before entering the room, which will not only allow a more personal feeling between presenter and participant, but also will eliminate precious time taken up at the beginning of each section.

Knowing the current status of the type of diets that are followed by each person is useful for the dietician and would save time in the classroom setting and encourage a more meaningful discussion during the class. Rather than going around to each individual, she would know ahead of time and could prepare specific handouts for each person specific to their needs. Also, by asking participants about the type of insurance used, it will enable the social worker to be prepared with information if a secondary insurance needs to be found, or if the person is not yet eligible for Medicare. Insurance questions are a common concern for many participants, although it is not typically a barrier that prevents treatment.

The final advantage to obtaining an EM from the individual is that it allows a personal aspect of their disease to be expressed. As seen in the interviews, I realized that few participants had the opportunity to tell their story about their disease. It was through the EM that I gained a deeper understanding of the perspective of the patient and saw the impact ESRD had in their lives. By the PrEP coordinator listening to the personal aspect of the each participant EM, the participant will express a more positive feeling of fulfillment from attending PrEP. This positive feeling will translate into further benefits, such as a better understanding of the material presented empowerment in being medical decisions and making the participant more comfortable in asking questions during and after the class. This will also eliminate many of the frustrations and barriers that participants experience, because they will be more comfortable in asking for help when needed.

5.3 PrEP Course and Content

There are some simple changes that could take place in order to create an environment in PrEP that is more comfortable. When participants arrive at the dialysis center have them put on pre-made name tags. Use two colors of name tags, one for participants and another for family or friends. This will allow the presenters and participants to get to know each other, and know who will be receiving treatment versus who is supporting the participant. This will eliminate awkward situations for the presenter, and allow them to know the role of each person in attendance. At the beginning of the class, the participants could introduce themselves tell a little about themselves, etc. This might help create a more relaxed setting where more questions would be asked and resolved. Also, by keeping the class small, it will encourage a more intimate feel and allow more questions to be asked. When there are too many people in the class, it may cause people to be uncomfortable and not ask questions. Another suggestion is to have them bring something to snack on during the break time. Many of these people are diabetic and have a difficult time going without food for so long. If they are able to eat something, perhaps they will absorb more of the information.

Another aspect seen in the interviews of this research project was the importance of social support. ESRD is a disease that not only affects the individual, but all those around that individual. Encouraging someone to come with them to the class can have a major impact. It can be a family member or friend, to be their advocate and remember certain points that can be very valuable. It is especially for those that have limited health literacy that a person attend with the patient in order to overcome it as a barrier. It is through that social support that help with treatment choices, lifestyle changes and self-management skills can be applied at home and severe health consequences can be avoided.

The section of PrEP where the dietician discusses the changes in the diet that the participants will experience because of their diagnosis of ESRD is extremely important. The diet portion of the class was very confusing to the participants. By having a clear break down of prevention/protection ideas and what is required before dialysis and after dialysis, greater motivation for diet change will occur. Many go to the class wanting to know what things they can do now to protect their kidneys or delay immediate dialysis. The cause for so many negative comments about the diet portion of the class was due to the frustration and confusion that many feel when told that their food habits need to change. By making this section more personal and through the use of the pre-PrEP EM interview, much of the confusion and frustration could be eliminated and would make the information more applicable. This will be accomplished through knowing what exposure each individual has had with diet restrictions, and what type of treatment they are most interested in. By simply having a handout with the diet requirements and restrictions for pre-dialysis, peritoneal dialysis and hemodialysis that the participants could take home would eliminate many of the frustrations.

There were specific concerns that prevented participants from continuing to be interested in peritoneal dialysis. Since it is advantageous for more patients to choose peritoneal dialysis over hemodialysis, certain issues should be addressed. It is significant when 15% of participants change their minds about doing peritoneal dialysis. It suggests that there is a need to increase the self-efficacy building of the peritoneal dialysis portion of PrEP. This could be as simple as having a cycler available for participants to look at, a PD patient available to answer questions, or walking them through the room where PD education takes place or where PD check-ups are done. It might even be resolved through finding out who might be interested in PD and having a current PD patient call them by telephone and talk to them about their experience.

By asking the participants to fill out an evaluation form after attending the course, crucial information to improve PrEP could be attained. It is imperative that the evaluation form be simple and brief. There should also be room for written comments.

Due to many participants not starting dialysis for a lengthy period, it would be efficacious to do a review once dialysis has begun. One of the nurses or someone from the dialysis staff could do a review of the PrEP during dialysis. It will mean much more to the patient once they have started dialysis and may answer many more questions. Encouragement of a family member or friend to be present during this review session would increase the amount of information absorbed and would encourage more questions.

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5.4 Publicity

Increasing the information that is available to the general public and those specifically affected by ESRD will not only increase the level of interest in PrEP, but will also improve the expectations of those that attend. If participants are more prepared prior to attending PrEP, their level of absorption will also increase. This can be accomplished through some simple modifications.

The information that is available on the Samaritan Dialysis Center Website about PrEP is currently at a 10th grade reading level. It needs to be changed to be more accessible to a broader audience and be more visually pleasing and interactive. Through the creation of an interactive Website, Pre-renal participants could go to and review the information received or view it before attending PrEP. Use of audio and visual presentations just like the ones used in the class setting could be used by putting the actual PowerPoint presentation as a link on the Website. By giving participants an opportunity to review the information before and after the class it would increase their level of comprehension.

Because of the elderly age of most participants, the use of the interactive Website might be difficult for those that need help because they don't have access to the Internet or have the necessary technological skills. For those without basic knowledge of computers, use of the computer labs and volunteers at the senior centers in Corvallis and surrounding areas could help them learn more about ESRD by using the SDC website. An alternative is to have the same information burned onto a DVD that can be taken home by the participants, and put into a DVD player on their home television. It could use the same slides and explanations as done in the presentation.

Any preparation before attendance at the class will help improve the expectations of the participants and create a better understanding between participant and the presenter. A basic information sheet or pamphlet about the PrEP available when the nephrologist invites the person to the PrEP would give the nephrologist an opportunity to answer basic questions about the class, and help the

participant know what to expect from the class. A poster including topics discussed and goals about PrEP in each nephrologists' waiting area could also encourage potential dialysis patients to attend the class. This also might encourage those who have already started dialysis or are in denial about their disease to attend the class.

Some of the recommendation are simple alterations to the current system, and others would require an investment of time and funding. However, these are all improvements that would be efficacious to the overall success of the program. They would result in not only the empowerment of the participants but a costbenefit for the dialysis center. It is obvious that each presenter is extremely busy, and making these changes will be time consuming, but the impact will be felt by all future PrEP participants. Based on the ability of the participants who are currently taking the education course and the positive consequences that are currently experienced by participants, imagine the amount of success that could be obtained through making a few alterations to make it even more successful and effective.

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Appendix A: Interview Questions

The following questions were used in the pre-PrEP interviews (Instrument 1) and the post-PrEP interviews (Instrument 2)

Instrument 1: Pre- PrEP Interview

1. Age

- 2. Current/Previous Employment
- 3. Level of Schooling
- 4. Location of Schooling
- 5. Ethnic Heritage
- 6. Family Setting

Number of Children (location)

Spouse (living)

Family Support

7. What do you call the illness that you are experiencing?_____

8. Tell me about the experience you have had in regards to _____, ie

the experience with your doctor, family. (name of your doctor)

- 9. What does this _____ mean to you? What does it mean to your family?
- 10. What do you think has caused _____?
- 11. Why do you think it started when it did?
- 12. What do you think ______ does to your body? (symptoms)

- 13. How severe is _____? What do you believe will happen with this sickness?
- 14. What kind of treatment do you think you should receive?
- 15. What are the most important results you hope to receive from this treatment?
- 16. What are the main problems ______ has caused?
- 17. What do you worry most about____?
- 18. What are your expectations of the Pre-renal class?
- 19. What and where have you received your information about ____?

Instrument 2: Post PrEP Interview

- 1. What did you think about the Pre-renal class?
- 2. Did it meet the expectations you had before the class started?
- 3. What do you now call the illness that you are experiencing?_____
- 4. What does this _____ mean to you? What does it mean to your family?
- 5. What do you think has caused _____?
- 6. Why do you think it started when it did?
- 7. What do you think ______ does to your body? (symptoms)
- 8. How severe is _____? What do you believe will happen with this sickness?
- 9. What kind of treatment do you think you should receive?
- 10. What are the most important results you hope to receive from this treatment?
- 11. What are the main problems ______ has caused?

- 12. What do you worry most about_____?
- 13. Do you have any complaints or suggestions about the Pre-renal class?
- 14. Which treatment will you choose?
- 15. Why did you choose that treatment?
- 16. Are there any limitations or barriers that prevent you from receiving the treatment you would prefer?
- 17. Are you concerned about the cost of dialysis? How will you pay for the treatment?
- 18. How will your diet change when you go on dialysis?
- 19. How has your family adjusted to your diagnosis?
- 20. Who will be your support network through your treatment?

(Reece et. al 2002)

Appendix B: S-TOFHLA

The following assessment is the Shortened version of the Test of Funtional 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. The license number 095/04 was issued October 12, 2004 for the purpose of this research project. 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 a. is. b. empty b. am. c. incest c. if. d. anemia d. it.

The X-ray will		from 1 to 3 _		to do.
a.	take	a.	beds	
Ь.	view	Ь.	brains	
с.	talk	с.	hours	
d.	look	d.	diets	

THE DAY BEFORE THE X-RAY.

For supper have only a		_ and jelly,	
	a. little	a. toes	
	b. broth	b. throat	
	c. attack	c. toast	
	d. nausea	d. thigh	

with coffee or tea.

After		, y	ou must not _			or drink
	a.	minute,	2	a.	easy	
	b.	midnight,	1	Ь.	ate	
	c.	during,	c	c.	drank	
	d.	before,	C	d.	eat	

anything at	until <u>after</u> you have	the X-ray.
a. ill	a.	are
b. all	b.	has
c. each	1 C.	had
d. any	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.	
	Ь.	drink,		Ь.	breath.	
	c.	dress,		c.	water.	
	d.	dose,		d.	cancer.	

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

- a. answers,
- b. exercises,
- c. tracts,
- d. questions,

- a. Department
- b. Sprain
- c. Pharmacy
- 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 in	formation 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. emphyser	na
b. applicatio	on
c. gallbladdo	er
d. relationsh	nip
the to get such pro	of. I that for
a. inflammation	a. investigate
b. religion	b. entertain
c. iron	c. understand
d. county	d. establish
Medicaid I must report any a. chan b. horn c. antao d. char	in my circumstances ges nones cids ges

•

within a. three b. one c. five d. ten	(10) days of becoming	a. award b. aware c. away d. await	of the change.
I understand a. th b. th c. th d. th	if I DO NOT lik nus his nat nan	a. marit b. occup c. adult d. decisi	made on my al pation on
case, I have the a. b. c. d.	to a fair he bright left wrong right	earing. I can a. b. c. d.	request refuse fail mend
hearing by writing	orth a. counting b. reading c. calling d. smelling	ne county where	I applied.
If you a. wash b. want c. cover d. tape	_ TANF for any family	a. member, b. history, c. weight, d. seatbelt,	_ , you will have to

_____ 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	· · · · ·	a.	hypoglycemia.	
	b. date		b.	eligibility.	
	c. meal		с.	osteoporosis.	

d. pelvic

- 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.

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Literacy		
	L	
	Date M or ID# 	Date F

July 1995 © Emory University

Large Print Version, English 14 point font • STOFHLA

STOFHLA: Reading Comprehension Scoring Key

Passage A	Passage A	Passage A	Passage B	Passage B	Passage B
Al 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	В30 с	
	-			B31 b	
-				B32 a	
-					
,	5141				

14 Point Font

STOFHLA • Large Print Version, English 14 point font

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Appendix C: Pre-PrEP Interview

In order to improve the PrEP, the dialysis staff should use a basic Explanatory Model during a phone pre-interview. This will allow the dialysis staff to understand the perspective of the participant, and help save time during the class. The following page is an example of what could be used

Pre-PrEP Interview

Name:							
Age:							
City of Residence:							
Nephrologist:							
 Questions: What do you call the illness that has caused you to be invited to this class? 							
 What is your kidney functioning level? 							
• What is the cause of this illness?							
 What do you hope to learn (expectations) from this class? 							
 Do you know what type of treatment you would like to receive? 							
 Are you on any special diet? 							
If so what do you avoid?							
• Is there anything specific you would like to learn from the dietician?							
 What insurance do you have? 							