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**Family Education, Occupation, and Chronic Illness: Social Class and the Lives of  
Hemodialysis Patients**

A Dissertation Presented

by

**Paul Eric Bugyi**

to

The Graduate School

in Partial Fulfillment of the

Requirements

for the Degree of

**Doctor of Philosophy**

in

**Sociology**

**(Concentration – Medical Sociology)**

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**Abstract of the Dissertation**

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A vast amount of evidence exists showing a relationship between socioeconomic status (SES) and health. Regardless of how outcomes are measured (self-reported health, incidence of disease, mortality rates and others), income, educational attainment, and occupation are key predictors. How SES matters for health outcomes has been a major question asked by researchers during the past 25 years. Many sociologists argue that the resources that come along with high socioeconomic status – money, power, prestige, beneficial social connections, knowledge, and skills – explains the SES/health gradient.

This research project assesses whether or not those resources were important to individuals in dealing with a chronic illness, specifically end-stage renal disease (ESRD) undergoing hemodialysis. A mixed-method design was used to determine if the resources mentioned were factors in making individuals good dialysis patients. A survey questionnaire was distributed to hemodialysis patients (N=82) to assess relationships between measures of socioeconomic status, resources, and patient adherence. Semi-structured interviews (N=17) were conducted based on findings from the statistical analysis. Observational data of hemodialysis treatment was also gathered and reported.

Although statistically significant relationships were found between measures of SES (father's education, individual's occupation) and patient adherence in the quantitative analysis, little evidence was found that resources explained the links between SES and adherence. In interviews, father's education mattered to patients because it provided a source of enrichment and stability for them that translated into a self-efficacious and positive attitude towards one's health. Further, having a clearly defined occupation from which patients drew upon as a source of identity buffered these individuals from having their illness define them. Respondents who did not have stable environments and meaningful careers felt trapped and defined by their illness, and struggled with many aspects of their treatment.

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## **Chapter 1: Introduction**

This dissertation examines how socio-economic status, and more specifically family background and an individual's occupational status, influences health. Of course the concept of SES is one that sociologists and other academics (or the public for that matter), rarely agree upon. However, it would be hard to find people who deny that being well-educated, having a good job, and having money in one's pocket isn't a good thing. In many western democracies (and now spreading further across the world), at least the idea of upward mobility is cherished and strived for. The goal is simply the attainment of a better life. Even practical Marxists who deny that upward mobility is a viable conception of life in capitalist society, such as argue for a better life as well, by rearranging human society collectively pursuing similar goals - having employment, being educated, and having the opportunity to consume objects that one enjoys.

As sociologists we are inclined to understand (down to the most miniscule detail) how SES affects peoples' lives for better and for worse. We know that having high SES provides more opportunity, more happiness, and healthier and longer lives. We know that having low SES increases the probability of poor outcomes in terms of job prospects, stress, and health. We know that the strata of society people are born into in many ways heavily influence the opportunities one has, and at the same time understand that SES is fluid, and that fortunes can change from one generation to the next. This present research provides, in a specific yet important way, an understanding of how SES and health are linked.

For the past 40 years, scholars in multiple fields (sociology, psychology, public health, economics and others), have laid out the vast body of evidence that shows a very strong link between measures of socioeconomic status and one's health. During the last half of that time period, research has progressed from describing the existence of what scholars call the "SES-health gradient" to research questioning why that gradient persists. Explanations of the gradient include stress, childhood environment, relative deprivation, biological and genetic differences, intelligence, control over one's labor, health as a means of distinction, and access (or lack of access) to financial, social, and educational resources.

This particular study is more narrowly focused on the chronically ill, examines how those with end-stage renal disease (ESRD) deal with their illness and their treatment regimen determined by their doctors. Analytically, the study measures the impact of SES on patient adherence to that regimen, and also focuses more specifically on the reasons those from different levels of SES do better or worse with their treatment. The life-course perspective and fundamental cause theory are the theoretical guideposts for this research project.

### **The Case**

Hemodialysis<sup>1</sup> patients die at an alarming rate. In 2005, there were 168 deaths per 1,000 patient yearzz. The hospitalization rate is almost 15 days per patient year. The number of people who die after they lose kidney function is significant; to live beyond five years on dialysis is rare. A substantial number of people receive kidney transplants and lead relatively normal lives. The rest are forced to undergo dialysis treatment, usually three times a week for about 3-4 hours each treatment. Treatments which range from mildly annoying to very unpleasant, can be deadly to the elderly and to those who do not pay attention during their treatments since mistakes can be extremely costly.

One of the reasons for the high mortality rates is that the health of a hemodialysis patient is determined largely by the patient's individual behavior. Despite warnings from their doctors, some patients often skip treatments, ignore dietary and fluid restrictions, and sometimes use illicit drugs. These patients tend not to live long. During their time as a dialysis patient, they spend a great deal of that time in the hospital due to complications from their behavior and cost the health care system a substantial amount of money.

Adherence<sup>2</sup> to the dialysis regimen has long been an issue for physicians, nurses and other healthcare providers. Most sources state that at least 50% of dialysis patients are non-adherent at some time during their dialysis careers (Haynes and Sackett 1976; Kugler et al. 2005). Non-adherence with various aspects of the treatment regimen - skipping treatments, high phosphorous,

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<sup>1</sup> Hemodialysis is used for people with End Stage Renal Disease – people who have little or no kidney function. Blood is extracted from the patient, “cleaned” in a dialyzer, and returned to the body.

<sup>2</sup> There is some debate concerning how to define the behavior of following physician orders. Compliance has typically been used in the past, while adherence has become more popular recently, perhaps due to the authoritarian feelings the word “compliance” entails. “Adherence” is used here.

high potassium<sup>3</sup>, fluid overload, and not taking medication - is associated with higher mortality rates. Due to the extremely high costs of healthcare in the U.S., the price of paying for the non-adherent is a very serious problem for society at large. Dialysis treatments alone are a heavy burden on resources, and complications can make costs exorbitant. The cost for dialysis in 2005 was \$32 billion in public and private healthcare costs; this cost, however, does not include the cost of complications that result from dialysis for procedures, surgeries, infections and hospital stays (Clearinghouse 2008).

Adherence is a difficult problem for patients. Dialysis treatments are generally uncomfortable. Large needles are inserted into the body to draw blood into a machine where it is cleansed through a dialyzer (or kidney), and then directed back to the body through another needle. Other than sitting in the chair for 3-4 hours at the site, people can experience pain in their accesses (fistulas, grafts, or catheters<sup>4</sup>), fatigue, or hypotention (a drop in blood pressure due to excess fluid removal). Hypotention can cause dizziness, fainting, nausea, vomiting, and even death if not dealt with quickly. Other complications, sometimes deadly, can arise if either the staff or the patient makes mistakes. Patients have at times pulled needles out, or needles have come out due to not being secured properly, leading to a large amount of blood loss. If air enters a person's bloodstream it may cause an air embolus that can lead to clots and, if not treated quickly, death. However, an observant patient, one who knows some of the early symptoms of hypotention and who is aware of his/her surroundings, can likely manage dialysis for many years.

Diet is a central feature of the dialysis patient's lifestyle. Every food imaginable has some level of potassium and phosphorous, so managing intake can be difficult. Foods high in potassium are tomatoes, potatoes, bananas, oranges, melons, chocolate, and most meat. Foods high in phosphorous are dairy products (notably cheese), chocolate, meat, nuts, and wheat bread. As is evident, most of these foods are staples of most American diets. Dialysis patients must be creative and careful with food choices, although medication can help some. Monthly blood work is done for most dialysis patients to monitor potassium and phosphorous levels.

Fluids are another problem for dialysis patients. Since most patients do not urinate, fluid overload can happen very quickly. Too much fluid in a person's system can lead to shortness of

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<sup>3</sup> The kidneys remove potassium and phosphorous. Too much of either in a person's bloodstream is extremely dangerous. Diet, dialysis and medication are the only ways to control these levels.

<sup>4</sup> These are "accesses," body modifications used to extract the blood in a sufficiently significant quantity.

breath, fatigue, heart problems, and death. Generally, the typical patient's fluid intake is restricted to 3% of his/her body weight between treatments, or about 2-3kgs (1-1.5 liters a day or between 32-48 ounces a day). Although these figures might not seem like much, if one has dialysis on Saturday and not again until Tuesday, it is quite easy to gain 5 kilos (or about 11 pounds). Then in a period of four hours or less, that fluid must be extracted from a person's system. The removal of large amounts of fluid over time can cause serious complications, particularly the enlargement of a person's heart.

Hemodialysis is a complicated, rigorous, and challenging treatment for those with kidney failure. It is worth understanding the mechanisms by which some patients can handle these challenges, or why some fail. While we might attribute these differences to a patient's personality, or perhaps their "character" (or "constitution" as one nurse called it), applying a sociological lens to an understanding of differences between "good" and "bad" patients will perhaps help us understand more clearly how the mechanisms of social class work.

### **Advantages of Using Hemodialysis as a Case**

The simplest explanation for why health improves generally as one moves up the socio-economic ladder is that middle and upper class individuals have financial resources that lead to better health, whether it be the ability to purchase health insurance, having access to good housing and sanitation, being able to purchase healthy foods and having the time to prepare that food. Perhaps surprisingly, economic resources (wealth, access to health insurance, etc.) seem to play only a partial role in explaining the SES and health gradient.

Regardless, if one could eliminate the impact of economic resources in a research study on health outcomes, especially a study that looks at a disease that affects people across the socio-economic spectrum, it would constitute a strategic research site (1982). Studying hemodialysis patients is a strategic site since the majority of the resources needed for treatment is, at least in the United States, funded by the federal government's Social Security program. Because any individual in the United States who has end-stage renal disease is eligible for Medicare, a major factor in creating an economic disparity (access to care), is thereby eliminated in this case.

Therefore, the differences that arise between persons of different socioeconomic status are limited to the behavior emanating from the individual, not economic resources.

Something must be said for the focus on adherence rather than health as the major outcome variable in this study. Most research on health inequalities tend to use self-reported health or mortality rates as outcome variables. If we look at health and mortality of a long course (which self-reported health and mortality measures), the mechanisms that link SES to outcomes are potentially clouded by myriad variables, particularly in the case of mortality. Using patient adherence as an outcome is an efficient means to understand how people approach their health without the obfuscation of potential confounders. Adherence strategies develop fairly quickly for dialysis patients (a few months), so linking strategies developed during this time back to SES is not as complicated a task. Adherence captures the attitudes of patients and their ability to deal with a health crisis. We should find during this tumultuous period in people's lives what resources they brought to the situation and what resources are brought to bear on managing their illness. While adherence to hemodialysis does not correspond to behaviors that one displays through the course of one's life to maintain their health, it certainly provides some clues to overall discipline and how much one values one's own life. If we can see people adapt in crisis mode, it can show us whether or not they have "what it takes" to be a good patient and avoid and deny complications and death.

### **The Problem**

This research examines why some patients comply with what doctors, nurses and other health professionals suggest, and why others do not. If we agree that health and illness are social phenomena, meaning that "health" and health care is inextricably tied into the social structure, we need to inquire into the advantages or disadvantages that some individuals have in terms of their position in that structure. The most central question of this research study concerns the resources (social, psychological, cultural, economic) that individuals bring to the experience of being chronically ill (in this case being on hemodialysis) that can potentially transform them into successful patients, and allowing them to survive at a higher rate.



### **Significance of the Study**

Findings from this research project are useful in many respects. First, the study is of great value to sociologists and other academics in that it places family background and education as the site of learned health behaviors and attitudes as opposed to seeing health behaviors and attitudes emanating solely from the individual personality level. Also, this type of analysis adds to the still growing body of literature describing the pathways from SES to health outcomes. Second, the findings should be of great practical use to nephrologists, dieticians, social workers hemodialysis nurses, and hospital administrators. The costs of non-adherence in hemodialysis are substantial in that non-adherent patients oftentimes end up in the hospital, in the end costing taxpayers in the United States since hemodialysis is paid for through Social Security. Understanding risk factors for patients, like low-SES background, can allow providers more information on how to improve adherence for their patients. Last, and most important, the findings have the potential to save lives. Many studies have shown that non-adherent patients are at a substantially higher risk of mortality. Understanding the major factors involved in patient non-adherence can provide an opportunity by providers and patients themselves to highlight and identify risk factors for non-adherence, and interventions could be developed centering on these risk factors.

### **Methods Used**

Three methods are used in this study for describing the connections between social background and medicinal regime adherence; quantitative, qualitative, and ethnographic. The first method is a quantitative analysis that assesses the main predictors of non-adherence among hemodialysis patients. For the quantitative analysis, a standardized questionnaire was developed to ascertain those aspects of social class predicting good and poor behavior as it relates to the hemodialysis regimen. Statistical analyses were then conducted to answer three central questions. First, are measures of socioeconomic status indeed correlated with non-adherence and general health? Second, do non-economic phenomena like social and cultural capital explain or mediate the relationship between SES and non-adherence and health? And third, are psychological factors such as depression the main reasons why patients do or do not follow the hemodialysis regimen?

The second method of investigation consists of 17 face-to-face semi-structured interviews focusing on the central finding of the statistical analysis – namely that father’s education and

occupational status predicts non-adherence. Respondents talk about a variety of themes in these interviews: how well they deal with dialysis; how they approach the difficult situation into which they are forced; strategies they employ to manage their health; what early family life and school was like; and how these early experiences shaped the way they approached hemodialysis treatment.

The third method employed is ethnographic, based on personal self-observations of more than six years as a hemodialysis patient. This auto-ethnographic narrative complements some of the findings in both the quantitative and qualitative analyses and fills in some of the holes not captured by the instruments used in these analyses. The chapter describes the difficulties involved in being a hemodialysis patient, the awareness needed to survive the dangers of treatment, and some of my personal experiences with disruptive or “bad” patients.

### **Organization of the Project**

Chapter 2 of this volume reviews the extensive literature on the relationship between socioeconomic status and health. A discussion of how SES is operationalized within the literature deserves some attention. Evidence of the modern SES and health gradient will then be provided. Following this, a short summary of each of the major paradigms in social class and health disparities research will show the ways in which scholars attempt to explain why this gradient exist. These perspectives include relative deprivation, stress, cognitive ability, life course, relationship to the means of production, cultural capital, and fundamental causality. How these perspectives inform this current project is explored, and how this relates to the specific research questions in this study is discussed.

Chapter 3 describes in detail the methodology employed in the study.

Chapter 4 reports the results from the statistical analysis of the survey data. Most notable of the findings is that father’s education and occupational status predict patient non-adherence, regardless of the education of the respondent. This finding provides some support to the notion that health behaviors and attitudes are transferred from one generation to the next. Also noteworthy predictors of non-adherence are self-efficacy and smoking. While measures of “resources,” or social and cultural capital, are associated with SES, they do not predict non-adherence.

In Chapter 5, semi-structured interviews are used to describe in detail the relationship between father's education and patient adherence and the relationship between occupational status and patient adherence. Questions to respondents are mostly focused on the ways that these individuals deal with the rigors of treatment, a description of their childhood and how their parents shaped them in terms of dealing with difficult circumstances, and lastly on their own careers/occupations and how that reality affects their approach to treatment. While it is difficult to measure the impact of an educated father's effect on their children in these interviews, what emerges is that it is not the education and the knowledge of the father per se that leads to better abilities, skills and coping mechanism among patients, but rather the patients with educated father had very structured and stable family lives, with expectations that their children would be well taken care of and invested in. That stability and investment from childhood pay off when people are faced with a crisis. In terms of the relationship between occupational status and adherence, patients with careers, not jobs, speak of their illness in terms of their occupation and how it impacts their occupation. Their careers provide an anchor for their lives, something to be proud of and a source of positive energy, that all other behaviors emanate from. Patients who are unemployed or simply work "jobs" do not have that anchor, and are more transfixed on their illness as defining their lives rather than the career that they have built previously.

Chapter 6 describes in some detail my personal experiences of being a hemodialysis patient. The intent of the chapter is to "fill in the holes" not captured by the surveys and interviews. The first half of the narration relates my personal experiences and describes in detail what being a hemodialysis patient is like. The narrative does not try to frame these experiences in terms of social class and illness, but rather provides the reader an understanding of why knowledge, skills, and positive attitudes are so important. As the narrative continues, many events and persons associated with dialysis are described who could not be brought into the fold in terms of traditional data gathering techniques since many of the people discussed would not be willing to participate in formal research. This small but important group of dialysis patients are all men, and exhibit defiant personalities. A number of these men had died during my course of time on dialysis. Discussions of the relationship between masculinity, social class, and non-adherence are discussed.

Chapter 7 stands apart from the empirical focus of the text as a theoretical attempt to deal with some issues that lie hidden by current conceptualizations of health disparities research. Most notably focused on here is adherence itself, a highly problematic conception if one does not take

the medical model at face value. Assumed in the medical model is the goal of normality in health experiences, with doctors and patients working together to achieve that status, with patient adherence being a major factor in that relationship. In many ways, adherence to a medicinal regime reflects a larger underlying structure of behavior that is indicative of general success in modern life. This idea harkens back to Parson's original concept of the sick role he developed in *The Social System*, where he argues that being unhealthy is about not being able to fulfill one's role expectations. Of course, Parson's conception was overly simplistic in that playing the sick role is not something easily achievable. With all of the complexities of modern life, including the demands of the market, the complex dynamics of the modern institution, and the lure of consumerism, playing the sick role properly depends on the resources one has to navigate that modern world.

Chapter 8 includes a discussion of the major findings, implications for both academic researchers and those who work in public policy, and questions for further research.

## Chapter 2: Review of the Literature, Theoretical Background

The research on the relationship between socioeconomic status and health is extensive, spanning almost two centuries and multiple disciplines. What early 19<sup>th</sup> century scholarship found of interest was the growth of poverty alongside urbanization and the population that was suffering from these changes. Vellmer (1989) in a study of French cities in 1840, found a relationship between poverty and mortality rates. In 1851, the British Government published the Decennial Supplements to the Annual Report of the Registrar General, a study of England and Wales showing mortality differentials by occupational class categories (Elo 2009). And although not an epidemiologist, Marx was surely interested in his analysis of social class, setting it up as the defining feature of industrialization. It is hard to imagine Marx not witnessing the physical exploitation and exhaustion of the urban proletariat, concerning himself personally with their fates and working towards their better overall health and well-being.

While it seems logical that 19<sup>th</sup> century policy-makers were concerned by the vast differences among the population and how those at the bottom of the economic scale were so severely affected, it is surprising that academics and policy-makers today are still concerned with these issues despite the tremendous improvements across the board in health and healthcare since the end of the 19<sup>th</sup> century. Since that time, mortality rates have fallen dramatically, mostly as a result the huge declines in both child and infant mortality. However, health and mortality differences among economic classes are still highly evident, and some evidence suggests that the gap is widening.

This chapter reviews the large body of literature that focuses on the evidence that socioeconomic status and health are linked, and explaining why this relationship exists<sup>5</sup>. Special attention must be paid to the fact that SES is a multidimensional concept, typically including some form of income or wealth, a measure of occupational status, and educational attainment. While all three dimensions of SES have been shown to be associated with various aspects of health,

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<sup>5</sup> The general field of “health disparities” looks at how both SES and race are factors in health outcomes. Blacks, Hispanics, and Native Americans are less healthy and die at higher rates than white Americans. There is a very large literature that discusses this large issue, but for the purposes of space, I will focus on SES in this review.

educational attainment has the strongest and most robust associations. While the relationship between SES and health has been shown to be consistent over time, the reason why SES and health are associated is still a question that has not been answered and continues to confound scholars. What is it about income, occupational status or educational attainment that leads to better outcomes? There are many promising findings in small studies, but unpacking the entirety of SES and the ways it influences health outcomes may be too momentous a task to achieve in a single study.

The first and most common conceptualization of social class in the health literature is socioeconomic status (or SES), and is used by scholars in a variety of disciplines: health economics, health psychology, nursing, public health, medicine, epidemiology, and to some extent, sociology. SES is operationalized in these studies by using one or more of the following measures: income; educational attainment; and occupation. The authors in this type of research rarely lay out the theoretical reasons why they choose one measure of SES over another. While sociologists are highly conscious that these measures are not mutually exclusive, there is a growing awareness in other fields that different measures of SES produce varying outcomes (Geyer et al. 2006). They might simply cite the fact that certain measures have been used in the literature in the past and so further elaboration or justification of that usage is not necessary. Since each of these measures is in essence capturing different facets of SES, this type of research, while providing interesting noteworthy findings, tells us little about the how SES actually operates.

Despite these issues, the use of socioeconomic status as an independent predictor of health is still standard in the literature. For a time, many epidemiologists used SES simply as a control variable for other important predictors of health. However, beginning with earnest in the 1990's, most researchers from many diverse fields interested in health outcomes began to consider and question why SES itself was such a constant predictor of mortality rates and overall health. While sociologists since the inception of the discipline used social class (or SES) as one of the central pillars of the study of society, economists, epidemiologists and public health researchers paid social class little mind. Now that researchers understand that SES is at the center of any understanding or prediction of health outcomes, many have turned to the theoretical concepts in sociology to understand health disparities.

The theoretical foundation for the majority of health disparities research in many disciplines (when theory is mentioned at all), is inspired in part by Max Weber's tripartite

conception of social class that sees one's relative rank in a population in terms of one's class, status and party (Weber 1946). The methodological approach is individual based, finding causal pathways between socioeconomic status of individuals (measured by income, occupational prestige, and educational attainment) and individual health or well-being scales, often including such measures as stress, health behaviors, or learned effectiveness. This approach is the most widely cited and most often used way of understanding health disparities, and use of this approach over time has led to a general consensus that education, income and occupational prestige are all consistent correlates of health and well-being in most developed countries (Veenstra 2007).

Using income, educational attainment, and occupations assumes a methodological individualist approach to explaining health outcomes. This style of analysis has been criticized (particularly by sociologists), because using SES ignores many contextual and environment factors that make up social class. Some have criticized the methodological individualists for being agentic, assuming some "choice" exists on the part of the individual to achieve some better health outcome (Cockerham 2005). Both Neo-Marxist and Neo-Weberian scholars are precise in their use (and their critiques), of modern operationalizations of social class. For instance, Scrambler and Higgs (2001), following Coburn (2000), are critical of Wilkinson's (1996) *Unhealthy Societies: The Afflictions of Equality*, where Wilkinson finds that countries with high income inequality have poorer overall health than countries with lower income inequality. The reason why countries with high income inequality are less healthy Wilkinson argues (following Putnam) is that there is a lower degree of social cohesion and trust. The challenge that sociologists present to Wilkinson's theory is one that forces researchers to understand the underlying reason of why class matters in this case, and to be much more precise in their analyses when drawing from statistical results that are based on nation-state level data. The goal, according to Scrambler and Higgs, is to explain the mechanism and the "reality" (Bhaskar 1978) of how social class affects health, rather than making large claims from simple statistical associations. Also, the measurement that Wilkinson uses in his research, income, captures only one piece to the puzzle of why inequality leads to health disparities. Income inequality is simply one form of inequality that has a multitude of confounders, and to reduce the explanation to social cohesion and trust denies the layer of reality where the process of that mechanism is actually taking place.

With these criticisms in mind, researchers from many different fields are beginning to flesh out what were originally statistical associations between SES measures and health outcomes such

as mortality and disease risk. The following review is a wide-ranging collection of the many ways that researchers measure the SES/health gradient and attempt to explain that gradient. While some attention in this review is placed on showing the associations between the various aspects of SES and health, the bulk of interest is concerned with those attempts to provide the intervening mechanism(s) linking SES to health. I begin with the facts concerning the relationship between SES and measures of health, and then speak briefly of the different attempts to conceptualize that relationship.

### **Modern Evidence of the Gradient**

The first important modern study exploring the relationship between SES and health is that by Kitagawa and Hauser (1973) which finds very large differences in mortality rates by educational attainment based on national US household data from 1960. Silver's contemporaneous study (1972) finds negative relationships between both median income and educational attainment with mortality. Also, Silver finds relationships between smoking and stress with mortality, paving the way for further research on health behaviors (smoking) and psychosocial factors (stress) that has become popular during the past 40 years. The Black Report (Townsend, Davidson and Whitehead 1992), commissioned by the British Government headed by Sir Douglas Black, looked at mortality rates among six distinct occupational categories in British society. Those at the lowest level of the occupational structure (unskilled laborers) had mortality rates 150% higher than those at highest level of the occupational structure (professionals); moreover, the gap between low and high SES had increased during the 30 years since the study was conducted.

Spurred by these initial findings, researchers have found strong associations between SES and mortality as well as SES and incidence of serious chronic illness. Susser et al (1985) find a gradient between five occupational categories and standardized mortality rates for a host of chronic conditions including malignant neoplasms, infectious and parasitic diseases, and diseases of the respiratory, digestive, and circulatory systems, while other research shows that from a list of 37 possible chronic conditions, 32 of those conditions were much more prevalent among those with less than 12 years of education than their more educated counterparts (Pincus, Callahan and Burkhauser 1987). Marmot and Shipley find a strong association between occupation and mortality



in their study of male civil servants (1996), while Stone et al (2010) find that simple indicators of overall health (general pain, headaches, and the flu) are determined by educational attainment and income. In terms of more specific diseases such as cancer (Adelstein 1980), and cardiovascular disease (Kaplan and Keil 1993) relationships between measures of SES and mortality exist.

There is also substantial evidence that the disparities between SES and health are widening. Pappas et al. (1993) find that the educational gradient with mortality had widened between 1960 and 1986, and Feldman et al (1989) show that much of the widening gap between education and all-cause mortality was due to deaths from cardiovascular illness. Masters et al (2012) finds support that this gap has continued to widen until the present day.

As research continued throughout the 2000s, scholars have taken a more sophisticated view of SES and have begun separating educational attainment, income and occupation as discrete variables as they are not a coherent phenomenon (Geyer et al. 2006). The ways in which these three measures affect outcomes are complex and often interact. Herd et al. (2007) find that educational attainment predicts the onset of disease, while income can predict the progression. What is becoming most clear is a growing consensus that educational attainment is the strongest predictor of health outcomes (Elo 2009; Schnittker 2004; Smith 2004; Smith 2007).

### **Mechanisms**

Adler and Ostrove (1994) claimed that the period of 1985-1995 was a “Decade of the Gradient,” reflecting all of the attempts to establish a full picture of the evidence linking SES to health outcomes. The authors go on to state that “1995 and Beyond” was to be a “Decade of Mechanisms,” arguing that henceforth the goal in all of these fields was to uncover the pathways that lead from SES to health outcomes.

### **Stress**

One of the major explanations for the SES and health gradient is stress. Those individuals from a disadvantaged social position experience more stress due to the adversity of their life circumstances giving them less ability to cope (Pearlin 1989). Sociological studies over several decades have shown consistent inequalities of both physical and psychological well-being

connected to level of SES (Thoits 2010). More specifically, researchers have shown those with low education, income, or occupational prestige have higher rates of psychological distress and mental disorders than those in more advantaged social positions (House 2002). Overall, poor and working class individuals have significantly more chronic difficulties in their lives and more cumulative burdens (Thoits 2010; Turner and Avison 2003; Turner, Wheaton and Lloyd 1995).

In Turner and Avison's 2003 study, those from a lower socioeconomic level (measured by a composite score of income, occupation, and education) experience higher levels of stress from these events than those from middle or higher SES positions (being African American and being female were also significant). The findings support the idea that those in lower status positions suffer from stressful events since they do not have the resources to cope, and hence have worse mental health outcomes.

How exactly increased stress leads to poorer overall health outcomes, however, is less clear. Some researchers theorize that those with low SES have more stress, which leads to unhealthy behaviors that try to mitigate that stress which in the end cause worse overall health.

According to Pampel et al. those who are economically deprived and live in disadvantaged neighborhoods have a variety of daily stressors: "...They struggle to make ends meet; have few opportunities to achieve positive goals; experience more negative life events such as unemployment, marital disruption, and financial loss; and must deal with discrimination, marginality, isolation, and powerlessness," (Pampel, Krueger and Denney 2010: 353) These stressors in turn lead to compulsive behavior (overeating, drinking, smoking, inactivity to name a few). One could conceptualize this paradigm as follows:



The research in this field provides indirect support for the stress thesis. For instance, Fagan et. al (2007) show that those who work in positions that are considered high stress tend to smoke more. High smoking rates are linked to single mothers with child-rearing duties (Graham 1995), being from a deprived neighborhood (Duncan, Jones and Moon 1999), and having low SES (Lynch, Kaplan and Salonen 1997). However, Pampel et al. (2010) argues that these findings should be taken with some reservations for two reasons. First, those with low SES report lower daily stressors and less severe stressors than their high SES counterparts, which suggests that more

research need to be done to assess which dimensions of stress mediate the relationship between SES and health. Secondly, there is an issue of causality since smoking and obesity may cause stress. There is some evidence that smoking causes stress by increasing nicotine dependency (Parrott 1999).

### Relative Deprivation

Partially related to the stress paradigm is a body of research that links differences in the status hierarchy to disease. Since the SES and health gradient is continuous all across the educational and income distribution (and most importantly at the higher end), it cannot be assumed that absolute deprivation is the source of all health disparities. As Marmot (2004) argues, low status creates stress, which therefore leads to lower health. Also, a sense of control over one's life leads to differentials in stress, and those at the higher levels of the social ladder have more control over their own labor.

The foremost statement of the relative deprivation thesis is in Richard Wilkinson's work, originally formulated in *Unhealthy Societies* (1996). In a small sample of advanced industrialized countries, Wilkinson shows that countries with higher income inequality have lower life expectancies. Some scholars have that these findings also exist between states in the U.S. and extend to health indicators other than life expectancy such as self-rated health (Kaplan et al. 1996; Kawachi, Kennedy and Glass 1999) The reason this relationship exists is because income inequality leads to "distressing social comparisons," (Schnittker and McLeod 2005: 81). People who live in areas with high income inequality are concerned about how they compare to others, causing status anxiety that leads to people feeling angry, deprived and marginalized. Also high income inequality in a country leads to low social cohesion and trust, reinforcing or enhancing status anxiety. Status anxiety either manifests itself as stress or other unhealthy behaviors (such as smoking or overeating) that lead to poor health.

However, a very large literature exists in response to Wilkinson's work, most of which fails to find support for the relative deprivation thesis, particularly when using fixed-effects models (Beckfield 2004). Depending on the type of study, the results are mixed for the relative deprivation thesis. Eibner and Evans (2005) find that when deprivation is measured relative to those in the same geographical state (New York, Minnesota, etc.), education, age group and race are factors which determine the potential of taking a health risk. On the other hand Pampel (2002) finds no

support that relative deprivation explains SES smoking disparities in the EU, and Chang & Christakis (2005) find no associations between income inequality and the possibility of being overweight.

### Latent Traits/Cognition/Intelligence

A small number of scholars (the first being Grossman [1972] ) maintain that the relationship between socioeconomic status and health is spurious, arguing that an antecedent variable explains the correlation. One group of arguments suggest that attraction to risk, a focus on short-term gain and low self-control both predict both low educational attainment and poor health behaviors (Gottfredson 1990). On the other hand, Gottfredson (2004) argues that the most fundamental cause of relationship of SES and health is overall general intelligence (measured and named as *g* in the literature). She argues that persons with high overall intelligence, a trait that is consistent throughout the life course, allows them to make effective choices about their health and to deal with complex illnesses and other health scenarios. In this cases SES is spurious since *g* determines both SES and health outcomes.

The evidence from the research is mixed, mostly due to issues of causality. Is it intelligence and self-control that determine both educational and health outcomes, or does social background influence both cognitive ability and self-control, leading to good health outcomes?

While Gottfredson suggests intelligence as an antecedent variable, Link et al (2008) show that education and income wash away cognitive ability's correlation with health. Auld and Sidhu (2005) find that intelligence explains part of the education and health gradient, but only at the lower end of the gradient. In other words, the causal effect of schooling on health is only relevant to those with low schooling and low cognitive ability. Cutler and Lleras-Muney (2010) provide the most extensive study in this area. They find that about 30% of the education gradient in health behaviors is explained by cognitive ability, but the majority of that cognitive ability is attained *during* schooling. Similarly, Calvin et al (2011) find in their meta-analysis that cognitive ability is correlated highly with mortality. While providing little support that childhood SES plays no role in mediating that relationship, adult SES accounts for a large percentage of the gradient, suggesting that the while cognitive ability is predictive of SES, it is the benefit of being from a high socioeconomic status that conveys the advantage, rather than solely cognitive ability. There are many studies in health psychology (see Deary, Weiss and Batty 2010 for a review of this literature)

that link intelligence and personality traits and their effects on health outcomes, but again the causal direction is unresolved.

### Marxist Findings

The most modern application of Marxist theory as relates to health outcomes generally follows Wright's (1978) neo-Marxist approach to social class. Axiomatic in this perspective is the notion that abstract categories (education, income, occupation) relating to aggregated groups of people are in no way representative of a "social class." The means of production is the underlying structuring mechanism in modern life, and creates the central realities that determine one's existence. Marxist scholars interested in health reject the dominant view of class indicative of the literature encompassing income, education, and occupation. The only way to properly measure social class is by adhering to Marx's central formulation – that social position is determined by the relationship to the means of production. Since Marx defines class by relationship to the means of production, medical sociologists in this tradition have operationalized the means of production in modern research by measuring the extent to which one controls one's own labor.

While Marxist analyses are not the dominant paradigm in research in health disparities, the literature in the Marxist tradition is extensive, particularly in the United Kingdom (Bartley et al. 1996; Borooah 1999; Fitzpatrick and Dollamore 1999; Hattersley 1997), and some from the United States (Muntaner et al. 1998; Schwalbe and Staples 1986). Veenstra argues that while some of the studies do show a relationship between control over one's work and stress, they have very little to say about whether "social class" has anything to do with health outcomes. More simply put, people could strive to attain positions with more control over their work to reduce their stress and improve their health. In reality, these studies suggest that having control over your work and being a boss is less stressful than being controlled, rather than illustrating social class as an objective phenomenon playing out in the workplace. Also, control over work does not equate to meaning that one owns or does not own the means of production, although admittedly they are highly correlated.

However, despite Veenstra's criticisms, the results from these studies shed an important light on the relationship between work and health, highlighting how having a job with control (and the status that is usually associated with that control), is highly advantageous. Not acknowledged in Veenstra's critique is the process by which one comes to have the type of job in which one has

control over his or her work. This socialization process one experiences as a “member” of a social class is not discussed in the Marxist literature on medical sociology, but exists ad infinitum in the stratification literature in sociology. With these thoughts in mind, being born into a particular background considered “middle” or “upper” class is certainly a resource one can use to obtain an occupation which entails a high degree of control and presumably lower levels of stress and better health. The Marxists deserve some credit for describing a possible link between control and health, although this line of research perhaps does not satisfy the larger questions and dynamics of political economy.

### Cultural Health Capital

Since providing support for a purely Marxist theoretical perspective of social class and health is such a monumental (and perhaps impossible task), some sociologists have turned to the work of Pierre Bourdieu, whose capital (or resource) model is less wieldy methodologically (and has less political baggage) than a Marxist perspective, and is more explanatory than most analyses characteristic of most quantitative work published in American social science journals.

There is a small but growing body of research that applies Bourdieu’s theory of distinction to health inequalities (Abel et al. 2011; Ackerman, Auer and Gonzales 2013; Dubbin, Chang and Shim 2013; Grineski 2009). In a way, good health is a way to distinguish oneself from those lower in the class structure. For instance smoking, originally used as a technique by the upper classes to distinguish them, is now largely stigmatized by the upper and middle classes. Smoking may be used by those of lower status to distinguish themselves as tough or independent (Pampel, Krueger and Denney 2010). Slimness, a good diet, and a healthy look are now markers of middle- and upper-class lifestyles.

Other researchers like Abel (2008), see cultural capital as useful for health without linking it specifically to using that capital to distinguish oneself. Janet Shim introduces the concept of cultural health capital (derived from Bourdieu’s concept of cultural capital), stating that it is “...the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal health care relationships.” (Shim 2010: 50). While focusing on the clinical encounter, the attempt is to “purchase” a healthy body through the activation of resources (Lo and Stacey 2008).

### Social Conditions as a Fundamental Cause of Health Disparities

The most comprehensive theoretical perspective that attempts to understand persistent health disparities by socioeconomic position is fundamental cause theory, originally conceptualized by Link and Phelan (1995). They draw from Lieberman (1987), who discusses the difference between basic (or underlying causes) and surface causes. Basic causes (in this case SES) will lead to changes in the outcome, while surface causes (like diet, exercise) may or may not affect health outcomes (Diez Roux 2012). Link and Phelan make a distinction between *proximate causes* and an *underlying fundamental cause* of health disparities. For the most part, the perspectives explored above in this review attempt to link proximate causes in the sense that they link specific mechanisms (stress, relative deprivation) to outcomes. Proximate causes are causes that are the closest in time to the outcome they produce. For instance, stress (caused by low control at work or a violent environment) is a proximate cause of behaviors such as overeating, smoking and drug use. *Distal causes*, on the other hand, exist further back in time in the causal chain. Distal causes of health disparities are intelligence, personality traits, or socioeconomic status. The generator of these specific outcomes across time and disease is referred to as a “meta-mechanism,” more encompassing than proximate causes, or simply “mechanisms.”

In a line of research, Link and Phelan argue that social conditions are a basic cause of health disparities. Since health disparities are robust over time (seen as far back as the early 19<sup>th</sup> century), new mechanisms for health inequalities emerge when those that exist are blocked or disappear. New mechanisms come about because persons with high socioeconomic status possess a wide range of flexible resources including money, knowledge, power, prestige and beneficial social connections that can be *purposively* used to achieve good health. As Diez Roux states, “These flexible resources ensure that persons of higher SES know about, have access to, can afford, and are motivated to engage in a broad range of health-enhancing activities, including behaviors and treatments and living or working in environments conducive to health (2012: 48). The gradient constantly reemerges over time because high SES persons, using these flexible resources, are able to prevent the onset and the progression of new diseases that become dominant as old diseases affect the greater society less. In the early 20<sup>th</sup> century the leading causes of death in the United States were pneumonia, diarrhea and tuberculosis. Persons with higher SES had from much lower rates of these afflictions because they had access to good housing, sanitation and physicians

(proximate causes or mechanisms). While sanitation and housing improved significantly during the course of the 20<sup>th</sup> century across the entire United States, mortality due to these factors dropped tremendously. By the mid-20<sup>th</sup> century there was virtually no difference between low and high SES in terms of mortality rates from these factors, and all groups had extremely low mortality rates from each.

However, while diseases and illness from lack of access to fresh water, poor sanitation and poor housing declined dramatically, new disparities arose from new diseases. Heart disease and diabetes are now some of the leading causes of death in the contemporary US, and mortality rates are affected greatly by SES. Since persons with low SES experience more stress, eat a less healthy diet, exercise with less frequency, have less contact with persons with medical knowledge related to their illness, and are less knowledgeable overall about these diseases, have higher rates of heart disease and diabetes, and have higher mortality rates once they are affected by them.

Two influential articles lend support for the theory. The first article (Phelan et al. 2004) is epidemiological in focus and attempts to show the role of resources in disease outcomes. The authors distinguish between highly preventable causes of death (kidney infections, cirrhosis of the liver etc.) and less preventable causes of death (multiple sclerosis, leukemia, etc.). The theory suggests that causes of death that are highly preventable should affect those with higher socioeconomic status to a much smaller extent since they are able to use flexible resources to mitigate the effects of disease and illness. For less preventable causes of death (which the medical field knows little about stopping), they argue that the relationship between SES and mortality would be minimal since resources are not as useful. In their analysis, hazards ratios for low preventability causes of death are fairly close between high and low SES persons. On the other hand, much higher hazards ratios are evident for low SES persons with highly preventable causes of death.

While Phelan et al. show how fundamental causality works across diseases using a large dataset, Lutfey and Freese (2005) show how SES operates through multiple pathways to produce different experiences of care for diabetes patients. In an ethnographic analysis, the authors compare two different diabetes clinics: one that serves persons of high SES (called the *Park Clinic*); and another that serves persons of low SES (called the *County Clinic*). Patients from the high SES clinic have much more continuity of care, which gave doctors more information to make a more tailored and effective treatment plan. Doctors at the County clinic were mostly residents who only



stayed with patients a few months, forcing them to make assessments of patients based on objective indicators of health (which doctors acknowledge as a poor proxy for overall well-being of their patients).

The Park clinic offered a variety of educational resources to patients for self-education while the County clinic offered little. Low SES patients were found to have many other constraints in their lives that led to serious challenges to good care. Lack of financial resources made it difficult to purchase medical equipment and medication, to have access to a gym, and to choose healthy meals. Also, many low-SES diabetes patients worked regimented jobs which made it difficult for them to be compliant with their medication schedule. Lastly, low-SES patients were forced regularly to deal with problems on their own – lack of social support being a persistent problem in this population.

### Life Course Approaches

The life course approach sees an individual's health status as being influenced by their social ties throughout their lives. The norms and values of young peoples' friends and their romantic partners are strong predictors of health (Bearman and Brückner 2001; Gaughan 2006). As people transition into adulthood, risky behaviors such as drug use, drinking alcohol and smoking tend to decrease, leading to better health (Rogers 1995), and as people marry their partners provide an incentive to be healthier (Bachman et al. 2001).

There is a great deal of evidence to suggest that what happens early in life, and the environment a child lives in, particularly their social environment, affects mental health not only for children but also much later for adults (Morgan et al. 2012; Stewart-Brown, Fletcher and Wadsworth 2005). One of the gaps in the literature of the life course approach is how family circumstances early in life might lead to better health behaviors later. In other words, do early childhood enrichment and support (or lack of it), lead to better health behaviors later in life?

### Summary

Fundamental cause theory represents the leading theory in epidemiology for conceptualizing contemporary class-based health disparities. All of the main mechanisms

discussed above that link SES to health (stress, relative deprivation, cognitive ability, relationship to the means of production, cultural and social capital) are generated by this meta-mechanism. To theorize that health in modern populations is completely tied to the power distribution in the social structure has powerful implications, a significant issue I will deal with in Chapter Six. While fundamental cause theory has been acknowledged as the way to go for understanding health disparities, direct tests of the theory are not commonplace, nor are they realistically achievable. In a sense, the grandness of the theory is significant enough that researchers are only able to capture the specific pathways between certain aspects of social class and health outcomes.

Since SES is at the heart of the discussion, it is important to understand the effects of stratification in modern societies at least to begin to approach this problem. Social stratification itself is a well-established and long-standing subfield in sociology, one with many problems still unresolved. One needs to be wary of using concepts and perspectives from the stratification research to understand health disparities when no clear answer yet exists. On the other hand, looking at the issues of social class through the lens of health outcomes might provide an outside perspective to a field grown weary with its internal-only discussions. Health economists, psychologists, and geneticists are now interested in an area of study that has been, for the most part, within the purview of sociologists. This requires the broadening of the borders of these disciplines, and researching what scholars are discussing in other fields without having to pay lip service to the word “multi-disciplinary.”

For sociologists it is necessary to provide a clear picture of how the social structure generates outcomes. Lutfey and Freese’s study of diabetes clinics offers an example of understanding the day-to-day inner-workings of class background and its affects with health. While the researchers show the importance of physical resources for diabetes care for high-SES patients (going to a good clinic, having regular doctors, having access to transportation, and having the ability to purchase the right medicine), the importance of non-financial resources are less apparent in their analysis. However there is a section in their article which focuses on the motivation of parents to adhere their regime. The question that needs to be answered in health research is how structural factors (early family life, educational and occupational experiences, neighborhood), create different practices of self-care and adherence. Also relatively absent from the epidemiological research on health disparities is how social background and early family life set the conditions for a healthy or unhealthy life. These questions must be assessed as well.

Outlined above is the basic theoretical orientation this research follows, namely the need to provide evidence of what links SES to good health outcomes. While having economic resources makes a difference for people in both preventing and managing illness, non-economic resources are of great importance as well, yet they are much less quantifiable. The central goal here is to measure the impact of non-economic resources in creating and perpetuating health disparities by socio-economic status.

### **Resources that Matter**

Link and Phelan (1995) argue that money, power, prestige, knowledge and beneficial social connections are the resources that high-SES persons use to obtain good health. How those mechanisms play out is an empirical question depending on the types of diseases and illnesses high-SES prevents, how high-SES mitigates the problems associated with different diseases or illnesses, and what resources in which case matter for creating health disparities. Despite the complexities in the myriad possibilities of why these resources create differences in health by SES (including the cases in which low-SES can be an advantage in producing good health (Dupre and George 2011), it is necessary to find the most generalizable mechanisms.

Due to the nature of the case used in this study, social-psychological conceptions are the most promising for understanding the consequences of social class on illness because these are the resources that will matter most (since economic considerations are mostly held constant). Therefore a majority of the variables used in this analysis will be drawn from sociological social-psychology, meaning they are conceptualized based on how social structures create psychological attitudes and consequent behaviors.

### **Inequality and Behavioral Differences: Potential for Divergent Outcomes**

The problem of patient compliance in hemodialysis is a problem of changing one's habits to fit the therapeutic regimen. In another sense, adherence as a dialysis patient is about discipline, moderation and denial of pleasure. One must also have a high toleration for frustrating

circumstances. Strange physical symptoms arise seemingly without cause; fistulas, grafts and catheters can malfunction; and friends that one sees at treatments can die. Depression is a common occurrence for many hemodialysis patients - a result of chronic pain, the curtailment of a previous “normal” identity, loss of a sense of control of one’s life, and physical setbacks.

Because the ability to deal with dialysis is largely a function of how a person can habitualize new behaviors (or slightly change existing habits), it would be beneficial to analyze patient compliance by using Bourdieu’s concept of *habitus* (1977). Bourdieu argues that persons operate consciously and unconsciously by dispositions, beliefs and habits embedded in bodies<sup>6</sup> and determined by their class location. If we can assume that the dialysis unit is indeed a field in which actors use their social and cultural capital to obtain other sources of power (in this case health), behavioral differences should arise in terms of the forms of capital that patients bring to the dialysis experience. The question we must try to answer is whether or not the forms of capital that persons from different class locations bring to dialysis have an impact on their health. First, we should look at examples of some observed differences between the working class and the middle class in institutionalized settings, trying to uncover which groups tend to navigate these spaces more successfully.

Lareau (2002) attempts to capture the mechanism by which aspects of cultural capital are obtained through the family in her discussion of the effects of differing child-rearing models between classes. Lareau argues that middle class parents engage in “concerted cultivation,” whereby children are encouraged to develop their talents by engaging in many organized leisure activities. Also, middle class parents develop their children’s language and reasoning skills by a variety of methods: explaining why a behavior is inappropriate; preparing their children for interactions with professionals; and having general discussions of daily routines centered around logic. Lareau illustrates that middle class children develop an “emerging sense of entitlement” in which they feel comfortable in institutionalized settings, most notably the classroom where these children will not feel intimidated by persons in positions of power. Bourdieu and Passeron (1977) argue that teachers identify those students who exhibit middle class traits, or those who have cultural capital, and privilege them over students who cannot display these behaviors and

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<sup>6</sup> Bourdieu, primarily drawing from the work of the phenomenologist Maurice Merleau-Ponty, rejects the traditional division in Western Philosophy beginning with Plato, elaborated by Descartes, and continued into the 20<sup>th</sup> century, that the mind and body are separate entities. Therefore, when I argue that beliefs are “embodied” they are not just thoughts one has. They actually are tied into the physical and emotional reality of a person.

dispositions. These dispositions are also important in other arenas of hierarchically structured social interactions, such as a doctor's office or a bureaucratic organization. Bourdieu's theory is that classes reproduce themselves by including or excluding individuals based on their ability to display class markers both consciously and unconsciously. In this case, children who learn to operate in middle-class circles with middle-class representatives (teachers, doctors, bureaucrats and other professionals), become members of the middle-class themselves by displaying middle-classes traits such as comfort in interactions, similarities in the consumption of art, music, and food, skilled linguistic capabilities, and the use of logical reasoning. One could hypothesize that middle-class dialysis patients would try to use their social and cultural capital to be successful in this particular field, leading to better health outcomes.

Working-class and poor parents do not foster the interaction of their children with other adults and persons in position of power, leading to an "emerging sense of constraint." Typically, poor and working-class parents engage in what Lareau calls "natural growth" when it comes to raising children, essentially letting their children develop on their own. The day is not overly structured, and the children are generally left to their own devices after school. As long as food, shelter and love are provided, poor and working-class parents seem satisfied with their own efforts. Working-class and poor children learn to feel trapped and constrained by institutional authorities since when their parents are forced into these situations, these parents feel inferior, ashamed, and tentative. Lareau implicitly argues that the classes have different ideas of how power operates: the middle class sees power as more fluid, something that they can use as part of their repertoire to get what they want; the working class sees power as fixed and hierarchical.

Encompassed in this natural growth model is a tendency towards obedience. Children are expected to obey their parents without question. In this sense, Lareau agrees with Kohn (1969) that obedience to authority is a central value that the working class wants to instill in its children. Obedience is problematic for our purposes in that it implies a strict power relationship, one that may force people to either extreme in terms of compliance. On the one hand, working class patients would become strict rule followers if in the past they internalized this rigid sense of discipline. On the other hand, working class patients could resent authority due to the overemphasis on obedience in childhood, and in effect could be defiant to authority figures. In this sense, working class habits may be beneficial to them since they may see doctors as Gods, yet they also may develop antagonist attitudes due to resentment.

Following this reasoning is Willis' (1977) analysis of working class high school students in England who disqualify themselves from middle-class careers by rejecting the authority of the school. According to Willis, it is not the middle-class institution (or those who represent it) that keeps them from being upwardly mobile, but rather a conscious and sometimes unconscious choice of these students to reproduce their class position. The "lads" as they call themselves, as opposed to the "ear'oles" (the students who accept the norms of the institution), create an oppositional culture to this dominant ideology. Willis argues that the conflicts between students and teachers reflect a similar series of clashes between the fathers of the lads and their superiors on the shop floor. The lads see the institution as "weak" and "impractical," an entity that serves no real purpose as opposed to their conception of "real work," i.e. the shop floor. The hostility that the lads develop in adolescence between themselves and the institution is the key factor in limiting them from participating in middle-class lifestyles.

Jean Anyon's work (1980) departs from Willis in that she sees schools themselves as institutions of developing inequalities. She argues that there is a "hidden curriculum" in working class, middle-class, and upper-class schools. In working class schools, teaching is a mechanical process in which students have no control over the content they learn, and in most cases antagonistic attitudes develop between students and teachers based on this strict hierarchy. In almost all cases, the reasons why answers are right or wrong are not explained. In terms of the other schools Anyon describes, depending on the socioeconomic background of the students, control over one's own learning is increasingly encouraged as one moves up the socioeconomic strata. Why Anyon's analysis is important here is that social class structures approaches to learning. Similar to Kohn, working class students learn to develop obedient approaches to authority and learning, while middle and upper class students learn to think creatively and to be agentic in their approach to knowledge, and later in life, their occupation. Again, similar questions are raised in terms of whether or not the obedience valued by working class parents is actually helpful. Approaching difficult health challenges might be more effectively dealt with by persons who are creative, confident, and willing to pursue their own intuition.

One of the goals of the following analysis is to determine if the class analyses of Bourdieu, Lareau and Willis are in some way applicable to dialysis treatment and adherence. These investigations are relevant in that there is an institutionalized setting where getting what one wants is determined by relationships with representatives of the institution, whether they be staff, nurses,

physicians, or administrators. If we assume that Lareau and Willis are correct that working class and poor individuals are “constrained” by institutions or create “oppositional repertoires” to dominant ideologies, it can be argued that interactions between themselves and institutional representatives within the dialysis world are less productive, more hierarchical, and less positive overall than are those interactions of the middle classes with institutional representatives. Feelings of hostility, resentment, and distrust should be prevalent amongst portions of this working-class or poor population, creating problems for health care professionals who need good information from patients to be effective.

### **The Hemodialysis Non-Adherence Literature**

The literature on hemodialysis patient compliance is extensive and yet there is little on which scholars and physicians agree. What is clear is that non-compliance with aspects of the treatment regimen is linked to higher mortality rates. The clearest example of this is hyperkalemia, or potassium overload. Since the kidneys excrete potassium, dialysis patients must be extremely careful with their potassium intake. Potassium is removed in limited amounts during treatments, yet builds in the bloodstream between those treatments. If the level rises too high, a patient could experience cardiac arrhythmia leading to sudden death.

Beyond the clear relationship between hyperkalemia and mortality, the relationship between chronic non-compliance with other aspects of the dialysis regimen and mortality has also been substantiated. Ganesh et al. (2001) found that persons with phosphorous levels greater than 6.5 mg/dl have a 41% greater chance of death from coronary artery disease and a 20% greater chance of death from sudden death, infection, and other unknown causes. Saran et al. (2003) found that skipping treatments was associated with a 30% higher mortality rate, and shortening treatments raised the mortality rate by 11%. Also, the researchers found that high interdialytic weight gain was associated with mortality, raising the rate by 12%.

Despite these statistical associations, compliance and mortality is not a well understood phenomena. O’Brien (1990) finds that patients who live well beyond the average time for dialysis patients to some extent are non-compliers. Of the 126 original subjects interviewed in her study, the 33 patients who survived nine years maintained that following the renal diet to perfection was

impossible and counterproductive in many ways. Some stated that not eating certain foods made them weak, while others said that they had to break the rules sometimes just to feel “normal.” These patients learned to “manage” their diet, fitting it to their individual physical and social needs. O’Brien makes an analytical distinction between “ritualized” versus “reasoned” compliance behavior, illustrating the decision of patients to either follow exactly the doctor’s order or integrating the regimen with their lives to achieve a sense of normalcy. To be a ritualist, according to O’Brien, could present its own problems, particularly the inability to enjoy eating and drinking – activities that are tied to social integration and are a source of pleasure.

The factors that researchers have argued are linked to compliance for dialysis patients are numerous, yet there is not a theoretically coherent framework for understanding non-compliance. Some authors find a link between depression and noncompliance (DiMatteo, Lepper and Croghan 2000; Taskapan et al. 2005). Typical non-compliers tend to be minorities (Leggat et al. 1998), males (Kugler et al. 2005; Safdar N 1995), smokers (Baines 2000; Kugler et al. 2005; Kutner et al. 2002; Leggat et al. 1998) and persons of low socioeconomic status (Baines 2000; Brownbridge and Fielding 1994; Chow et al. 2005; O’Brien 1980; Safdar N 1995).

One of the major focuses of the compliance literature is the impact that social support has had on both patient compliance and mortality rates, specifically amongst dialysis patients. At least two studies show a relationship between strong social support and lowered mortality rates (Christensen 1994; McClellan, Stanwyck and Anson 1993), and other studies illustrate a relationship between social support and patient compliance, both for dialysis patients and others with chronic illness (Boyer et al. 1990; DiMatteo 2004; Gallant 2003).

Despite these associations, there is no overarching theoretical framework for understanding habitual non-compliance and how it is understood from both the perspective of the patient and that of physicians and staff. However, many of the aforementioned variables seem to revolve around the same demographic: poor, depressed, lonely, disenfranchised individuals who smoke. Is this picture drawn from simply looking at a collection of variables that might or might not be related in any real theoretical and meaningful way, or does it actually describe the typical non-complier?



### Chapter 3: Data and Methods

The previous chapter discusses the possible mechanisms that link SES to health. In this analysis, I assess the following research questions. First, are education and occupational status predictors of adherence to treatment? Second, are measures of cultural and social capital predictors of non-adherence? Third, are psychological variables like depression the major predictors of non-adherence?

A mixed-methods approach is taken to understanding the relationship between SES and adherence. The first step in the analysis consists of a series of OLS regression analyses intended to answer two major questions. Are people adherent or non-adherent based on the resources they have due to their social status and; are people adherent or non-adherent based on the social status of their parents? These two research questions are based upon fundamental cause theory/cultural reproduction theories on the one hand, and life course theories on the other.

The second method of this investigation is qualitative and involves understanding the statistical associations that were established in step one. Semi-structured interviews were conducted to assess what links might exist between early family life, occupational status and health.

Lastly, I have included an ethnographic narrative of my personal experiences with dialysis. Those experiences were the basis for the more formal questions asked in both the quantitative and qualitative analyses. The ethnography is not “scientific” in any way, but it does convey a sense of what it is like to be a dialysis patient. Also, there is an extended discussion of the problem patients that are typically not included in data gathered from surveys since these people are generally not the type of people who volunteer to do surveys. That fact was uncovered during the course of my recruitment for subjects. According to the nurses, all of the patients who declined my requests for either an interview or a survey were not good patients and were generally disliked by the staff of the dialysis facilities. I believe it is very important to provide a recording of my interactions with these individuals, because they typify a layer of reality that is not captured by traditional sociological methods. More detailed discussions of the methodology used in each case are reported below.

## **Quantitative Analysis**

The quantitative data come from a constructed standardized questionnaire given to 82 respondents from four out-patient dialysis centers between April of 2010 and July 2013. Three of the centers are from suburban areas of the US northeast, and one center is located in a medium-sized city in the mid-Atlantic region. Collection methods varied at these different centers due to differences in policies regarding researcher-patient interaction.

Center One consisted mostly of outpatients but also was in close proximity to (and had organizational ties to) a large research and teaching hospital. Many of the patients who received treatment at the center were mentally incapable of completing the questionnaire<sup>7</sup>. I consulted the nurses about which patients would be able to fill out the survey. I then approached the patients and introduced myself as a university student doing research on dialysis patients and asked if they would be willing to fill out the survey. Some patients filled out the survey while undergoing treatment, and other patients took the survey home. For patients who took the survey home, I followed up with them to see if they had brought the survey back. In all, 20 patients had returned questionnaires, with a response rate of 53%. Center Two was similar in the sense that it was in close proximity to a large hospital and had a large number of patients who were mentally incapable. Only 11 patients returned questionnaires with a response rate of 27%.

Before recruiting respondents at Center Three, I changed the protocol to include a financial incentive of a \$10 gift card to a local coffee shop to increase the response rate. The incentive was apparently successful as 32 patients turned in questionnaires - a response rate of 78%.

Center Four was physically attached to a large research and teaching hospital. The institution did not permit researchers to physically recruit patients face to face. A flyer advertising the research project was posted at various locations by the staff. Staff members let patients know of the research opportunity and that there was a financial incentive of a \$10 gift card. If they wished to participate, patients filled out the questionnaires and were given an envelope to mail them back to me. Eighteen patients completed and returned the questionnaires - a response rate of 43%.

The advantage of the survey is that it includes items that existing sociological datasets on health do not contain, such as measures of social and cultural capital, leisure activities, self-efficacy, and psychological reactance. More important, socioeconomic status is rarely measured

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<sup>7</sup> A high percentage of outpatient hemodialysis patient have minimal mental function. There was no objective way to assess whether these individuals could complete the questionnaire, so I asked nurses which patients would be able to complete the survey.

in non-adherence studies despite the tremendous amount of research concerning SES and health. The shortcomings of the survey is the low response rate for patients (due to the length of the survey and also because many patients are not well enough to complete it) and the lack of desirable objective indicators for the dependent variable non-adherence. Obtaining “objective” measures of adherence (blood levels on phosphorous, potassium, Kt/V) was not possible due to dialysis facility rules.

## **Measures**

### **Dependent Variables**

1. *Subjective Adherence*. The dependent variable used is subjective non-adherence to the hemodialysis regimen, which includes fluid intake, monthly blood work reports from physicians, and time missed on the machine. Respondents were asked how often they gained more fluid than they were supposed to and the average amount of fluid that they typically took off. They were asked how often doctors had to discuss high phosphorous and potassium levels during monthly blood reports. They were further asked how often they took off the machine early and how much dialysis time they missed when they came off the machine early. Cronbach’s alpha was used to test the reliability of the scale ( $\alpha = .691$ ). Principal component analysis was used to create a factor variable of non-adherence ( $\lambda = 2.34$ ).
2. *Self-reported health status*. Scored on a 1-7 scale. Even though dialysis patients generally report less energy and comfort than those persons without a serious health condition, it was important to ascertain if there were factors leading to subjective assessments of one’s health despite having end-stage renal disease. The value of adding self-reported health as a dependent variable is to see if the SES/health gradient persists when individuals are chronically ill.

### **Independent Variables (Socio-economic Status, Sociological Variables, Psychological Variables)** Socioeconomic Status

Two variables used to measure the respondent's and respondent's parents socioeconomic status: level of education and TSEI (total socioeconomic index) scores based on Hauser and Warren's occupational socioeconomic index (1997).

*Level of Education (Self, Father, Mother).* Coded as did not finish high school, high school graduate, some college, 2-year degree, 4-year degree, and advanced degree (0-5). Missing data on the education variable (self, father, mother) was predicted based on the TSEI score of the respective person. Average TSEI scores were calculated for each level of education the person with missing scores had (again self, father, mother) and then substituted in for the missing education score. If TSEI was missing for self, father, mother, in addition to the education score, education scores were predicted based on either individual's education scores or father's education scores. If no education or TSEI data did not exist for self, father, mother, the lowest score was assigned to education. If a person had no idea what their father's or mother's education or occupation was, we assumed that the father/mother provided little or no benefit to the respondent, justifying the minimal score (0).

*TSEI Scores (Self, Father, Mother).* Hauser and Warren constructed a scale of SES based on the economic ranking of a profession. The authors developed a prestige score of each occupation as well, but the results using prestige scores in this analysis do not predict any significant findings, so TSEI is used in this study as one of the main measures of SES. Missing data on TSEI values is predicted based on the education of the person (self, father, mother). If no education values existed for these persons, TSEI was predicted based on either self or father TSEI scores. Similar to the education variable, if no data existed for any of the persons then the lowest score was assigned. "Housewife" occupation was not included in Hauser and Warren's scale, and so father's TSEI score was used in these cases for mother.

### Social and Cultural Capital Independent Variables

1. *Perceived social support.* Respondents were asked to what extent they could rely on five groups of people in terms of general advice, material support, and emotional support. The

five groups are family, friends, doctors, nurses and other patients (scale from McDowell and Newell 2006). A few studies have found that social support predicts adherence (Boyer et al. 1990; Christensen et al. 1992; Christensen 1994; Cummings et al. 1982; DiMatteo 2004; Gallant 2003; McClellan, Stanwyck and Anson 1993; Morgan 2000; Patel, Peterson and Kimmel 2005). Cronbach's alpha was used to assess the reliability of the scale ( $\alpha = .895$ ).

2. *Structural social support/social capital*. Shim (2010) argues that beneficial social connections create a knowledge base of health strategies. Theoretically, having access to friends, and especially friends with resources and education, would make a person much more likely to deal with the rigors of hemodialysis in a positive and focused manner. This measure assesses the number of friendships an individual possesses, the current activeness of those friendships, and the social status of the people who are friends. A position generator (Lin and Dumin 1986) was constructed to assess both the strength and number of social ties and the associated prestige of those ties. Respondents were asked how many friends they had from a list of people in ten specific professions (0-4+) and whether or not the respondent still had contact with each person. TSEI scores were used to measure the prestige of the associated professions. To construct a social capital index the number of friends was multiplied by the TSEI of the profession. Cronbach's alpha was used to assess the reliability of the scale ( $\alpha = .868$ ).
3. *Leisure Activities*. One of Bourdieu's (1984) major signifiers of class status and distinction is engagement in specific leisure activities. These activities reflect an attitude of the individual that focuses on sophistication, fitness, and intelligence. Respondents were asked if they had participated in leisure activities during some part of their lives from "never/I don't know what that is" to "all the time," and also whether they still participated in these activities. Leisure activities were coded as low vs. high-brow (for example bowling is low-brow and sailing is high-brow). Scores from 0-4 were calculated on each activity and two points were added to each activity in which the respondent still participated. Also, high-brow activities were multiplied by a factor of two to give added strength to the distinction-centered activity. The logic of this scale, similar to the position generator, is that it assesses

participation in leisure activities (a form of social support or social integration to use Durkheim's term), and the status signifier of the activity. Cronbach's alpha was used to assess the reliability of the scale ( $\alpha = .744$ ).

4. *Faith in Institutions*. A key component of Bourdieu's original analysis of cultural capital is that middle and upper-class individuals have the most to gain from the major institutions in society – schools, government, healthcare services, the police, banks, and government. Since individuals who are gatekeepers in these institutions come from the educated and wealthy classes, an affinity exists between those gatekeepers and clients from similar backgrounds. In effect, those with the most confidence in these institutions should be those who have the most success dealing with these organizations, and to use the resources offered by them to have better outcomes. Respondents were asked how confident they were in educational, health care, governmental, religious, banking, and law enforcement institutions from “very unconfident” to “very confident.” A scale was then constructed of these seven items. Cronbach's alpha was used to assess the reliability of the scale ( $\alpha = .883$ ).
5. *Comfort in Institutional Settings*. This variable coincides to a great extent with confidence in institutions; but rather than assessing a general attitude toward institutions that would theoretically most benefit those from the middle and upper classes, this variable measures the comfort individuals have in these settings. Being confident and comfortable in public is one of the great benefits of being in a superior social class position and should entail positive outcomes in these experiences. Respondents were asked if they felt comfortable in job interviews, applying for a loan, asking doctors questions, speaking in public, talking to the police, and asking questions as students. A scale was then constructed for these six items. Cronbach's alpha was used to assess the reliability of the scale ( $\alpha = .916$ ).
6. *Self-Efficacy*. Self-efficacy is the belief in one's abilities in accomplishing what is necessary in a situation. This variable could be classified as either sociological (Shim 2010) or psychological (Bandura 2001) since research suggests that self-efficacy is both an underlying personality trait and something that develops in social circumstances.

Respondents were asked to what extent they could deal with various aspects of their lives while undergoing hemodialysis. A scale was constructed based on responses to three items: whether patients could manage daily tasks; deal with the emotional challenge of dialysis; and remain active in maintaining good health despite dealing with treatments. Each item was a seven-point scale ranging from zero (least confident) to six (most confident). Cronbach's alpha was used to assess the reliability of the scale ( $\alpha = .796$ ).

### Psychological Independent Variables

1. *Psychological Reactance*. Reactance theory states that when freedom to act is removed from a person, the person tends to react by attempting to regain that loss of freedom (i.e. people will want something more when it is taken from them). Respondents were asked to what extent the loss of freedom due to the dialysis regimen caused them to feel the need to recover the lost freedom. There are two items to measure psychological reactance. The first item measures on a scale from zero (very angry) to six (not angry at all) whether respondents get angry when people tell them what to do (as opposed to suggesting behavior). There is a separate item that asks "When someone tells you that you can't have something that you enjoy, it makes you crave that thing more." Answers range on a four-point scale (coded 0-3) from "Strongly Agree" to "Strongly Disagree." (Dillard and Shen 2005; Fogarty 1997; Fogarty and Youngs 2000).
2. *Depression*. The Beck Depression inventory was used to assess the degree of anxiety and depression among respondents (Beck et al. 1988). The BDI, a 21-item inventory, was reduced to 14 items in this study since the seven of the questions could be confused with symptoms associated with being on hemodialysis (lack of appetite, tiredness and fatigue, irritability). There is a great deal of previous research on the relationship between depression and hemodialysis non-adherence. (Bisschop et al. 2004; Burton et al. 1986; Devins 1981; DiMatteo, Lepper and Croghan 2000; Drayer et al. 2006; Kimmel 2002; Kimmel and Peterson 2005; Tossani, Cassano and Fava 2005).

3. *Locus of Control*. This concept measures the extent to which one believes that one can control surrounding events. Those with high locus of control have internal control which allows them to control their own behavior by setting limits. Those with low locus of control respond better to external control, meaning that they generally act as the situation determines. Locus of control is an important variable in health psychology, as people with low locus of control tend to be less healthy (Furnham and Steele 1993). This variable, which asked patients whether they respond to symptoms (external control), versus putting limits on their behavior (internal control), was coded as a dummy variable.

### Control Variables

1. *Sex*. A dummy variable with men coded as 0 and women coded as 1.
2. *Race*. A dummy variable with white coded as 0 and non-white coded as 1.
3. *Smoking*. A dummy variable with non-smoker is coded as 0 and smoker is coded as 1.
4. *Age*. An interval variable with categories 20-30, 31-40, 41-50, 51-60, 61-70, 70+.

### Qualitative Methods

The qualitative analysis section of the dissertation does not stem from a set of propositions in the literature, but rather results from the findings in the quantitative analysis. As described in the next chapter, there are two key predictors of non-adherence that are shown from the statistical analysis: father's education and individual occupational status. The focus in the interviews is to determine the mechanisms by which these markers of socio-economic status impact non-adherence.

The seventeen participants are undergoing or were previously undergoing kidney hemodialysis. Pseudonyms were used for all respondents. Of the twenty one individuals I approached at the facility, sixteen assented to be subjects (a response rate of 76%). Interviews took between 30 minutes to 90 minutes. Five of the participants were women, and twelve participants were men. Fifteen of the respondents were white, one was Latino, and one was African American. Ages of the participants ranged from 45 to 80. All but one of the participants, received dialysis



treatments at a free-standing, non-profit, out-patient dialysis facility in a middle-class, suburban location in the U.S. Northeast. All of these patients received dialysis on Tuesdays, Thursdays, and Saturdays between 11 a.m. and 7 p.m. IRB approval was received from the company's IRB. The participant not from the facility I have mentioned, Harold, is a family associate and agreed to participate. The sixteen other participants were recruited by asking the nursing staff at the facility which patients were capable of completing the interview. As stated earlier, many hemodialysis patients are not mentally capable of completing a questionnaire or interview, and it was the nurses' decision to make that judgment. After receiving this information I approached the prospective participant and explained that I was conducting a research study on dialysis patients and asked if they would like to participate. I notified these individuals of their rights as research subjects if they agreed to participate.

A relevant point to be made here is that oftentimes the nursing staff tried to direct me to patients who were "good" patients or were "nice" people. I oftentimes had to remind the nurses that I needed to include as many participants as possible in the study, and that it was necessary to interview the "bad" patients. Also, oftentimes the nursing staff mistook "niceness" for SES. Many of the patients nurses directed me toward were friendly with staff, had nice jobs, and were "good" people. Some of the "bad" patients, as I approached them, were skeptical of me. One man, who was wearing sunglasses, said "No" before I even introduced myself. Another man, as I explained what I was asking him, interrupted me and with a somewhat hateful look said "no." One young woman simply ignored what I was saying to her.

## Chapter 4: Quantitative Results

Table 1 presents the mean, standard deviation and range of the two dependent variables in the analysis. About half of the sample is moderately non-adherent and another 12% non-adherent providing evidence that living up to the standard set by physicians is very difficult (Table 2). Also, as shown in Table 2, about 33% of respondents reported that they were in poor health.

**Table 1. Descriptive Statistics of The Dependent Variables: Self-Reported Non-Adherence and Self-Reported Health (N=82)**

	M	SD	Range
Self-Reported Non-Adherence (0-27)	5.67	3.66	0 to 18
Self-Reported Health Status (1-7)	4.58	4.53	1 to 7

**Table 2. Percentages of Respondents Adherence and Self-Reported Health (N=82)**

	Percentage
Adherence (0-3)	34.1
Moderately Non-Adherent (4-9)	53.7
Very Non-Adherent (10-18)	12.2
Good Health (6-7)	4.9
Moderate Health (3-5)	62.2
Poor Health (1-2)	32.9

Table 3 presents demographic information of the sample. Fifty-six percent of respondent are men and forty-two percent are women, which tends to reflect incidence rates of the sexes nationally. Sixty-one percent of the sample self-identify as whites while thirty-seven percent identify as non-white (26% Black, 7% Hispanic, and 1% Asian). Many respondents have at least some college (61%), and 20% of respondents are smokers. The mean age of respondents in the sample is 59 years of age.

**Table 3. Descriptive Statistics of Demographic Variables (N=82)**

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	Percentages
Sex	
Male	56.1
Female	41.5
Missing	2.4
Race	
White	61
Non-White	36.6
Missing	2.4
Education	
Did not finish high school	14.6
High school diploma	23.2
Some college	25.6
Two-Year college degree	13.4
Four-Year college degree	14.6
Advanced degree (Masters, JD, MD, PhD)	7.3
Missing	1.2
Smoker	
Non-Smoker	78
Smoker	19.5
Missing	2.5
Age	Mean = 59.35 years

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Table 4 presents correlations between demographic variables and non-adherence. A positive correlation exists between smoking and non-adherence (.23\*), while no correlation exists between non-whites and non-adherence (.17) or between age and non-adherence (-.18). The association between sex and non-adherence is negligible (-.06). The distribution of age and non-adherence takes the form of an inverted U-shape. Non-adherence increases as respondents approach age 60, then it starts to lessen as people get older. Seventy percent of respondents in the sample who were very non-compliant were 55 years of age or younger, while 46% of the most compliant patients were over 70 years of age. While non-whites made up only 37% of the sample, they accounted for five of the ten respondents in the sample who were very non-compliant. Also, while 56% of the individuals in the sample are men, 7 out of 10 persons who were very non-compliant were men.

**Table 4: Correlations between Non-Adherence and Demographic Variables (N=82)**

	Race (Non-White =1)	Sex (Female=1)	Smoking	Age
Non-Adherence	.171	-.063	.229*	-.183

\*. Correlation is significant at the 0.05 level (2-tailed).

Table 5 reports correlations between different measures of socio-economic status (including data for fathers) and non-adherence<sup>8</sup>. All measures of SES have negative correlations with non-adherence (meaning that those higher in SES are more adherent patients), while educational level (-.24\*) and TSEI scores (-.28\*) are statistically significant. Father's educational level (-.31\*\*) and father's occupational prestige (-.25\*) are both correlated with the respondent's adherence.

**Table 5: Correlations between Non-Adherence and Measures of SES (N=82)**

	Education level	Father's education	TSEI	TSEI score for father	Prestige	Prestige score for father
Non-adherence	<b>-.240*</b>	<b>-.307**</b>	<b>-.280*</b>	-.184	-.044	<b>-.248*</b>

\*. Correlation is significant at the 0.05 level (2-tailed).  
 \*\*. Correlation is significant at the 0.01 level (2-tailed).

According to Bourdieu's theory of cultural reproduction, the skills that accrue from education are in some ways minimal, and educational outcomes are simply an amplification of underlying class characteristics. In other words, educational success comes from good training in childhood. Educational attainment is simply a result of the full array of capitals that social class can confer on a person – both social and cultural. In a sense, the ability to succeed as a dialysis

<sup>8</sup> Mother's measures were not included since there are so little variance in mother's status. More than half of the respondents in the study were above 60 years of age, and most of their mothers were either housewives or did not go to college.

patient theoretically would social and cultural capital, variables which would be correlated with educational attainment and dampen education's effect on non-adherence when controlled for.

Table 6 shows correlations between educational attainment and measures of cultural and social capital. Educational attainment has moderate and statistically significant associations with High-Brow leisure activities (.41\*\*), social capital (.32\*\*) but no correlation with comfort in social situations (.14), social support (.14) or confidence in institutions (-.06). Educational attainment is associated with various measures of social and cultural capital, providing minimal support for Bourdieu's theory. Correlations between TSEI and measures of social and cultural capital are much weaker than that of education. Of the five variables listed here, confidence in institutions (no correlation) is the only variable that indicates attitudes about these institutions rather than actual behavior. Correlations between the measures of social and cultural capital with non-adherence are much less substantial (see Table 7). No associations are found between non-adherence and High-Brow leisure activities (-.15), social capital (-.18), social support (-.17) and comfort in social situations (-.13) and confidence in institutions (.05).

**Table 6. Correlations between Measures of SES and Social and Cultural Capital Variables (N=82)**

	TSEI	Education level	Comfort with authority figures	Leisure Activities	Confidence in Institutions	Social Support	Social capital
TSEI	1						
Education	.584**	1					
Comfort	-.102	.141	1				
Leisure	.297**	.411**	.116	1			
Confidence	.029	-.066	-.445**	.099	1		
Social Support	.047	.138	.074	.142	-.059	1	
Social Capital	.214	.323**	.090	.457**	-.087	.441**	1

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\*. Correlation is significant at the 0.01 level (2-tailed).

**Table 7. Correlations between Non-Adherence and Social and Cultural Capital Variables (N=82)**

	Non-adherence	Comfort with authority figures	Leisure Activities	Confidence in Institutions	Social Support	Social capital
Non-adherence	1					
Comfort with authority figures	0.125	1				
Leisure Activities	-0.15	-0.116	1			
Confidence in Institutions	0.05	.445**	0.099	1		
Social Support	-0.165	0.074	0.142	0.059	1	
Social capital	-0.181	-0.09	.457**	0.087	.441**	1

\*\* Correlation is significant at the 0.01 level (2-tailed).

Considering Table 8, when using education as predictor of non-adherence, controlling for measures of social and cultural capital, fail to affect non-adherence in any substantial manner yet do raise the R-squared from .057 to .090. At the same time, the relationship between education and non-adherence is washed away (standardized coefficient for education drops from -.240 to -.150), providing limited support that social and cultural capital explain the relationship between educational attainment and non-adherence. When TSEI is used as the measure of SES in the model (Table 9), TSEI remains statistically significant and the effects of social and cultural capital are not significant and explain little variance in the dependent variable.

**Table 8: Regressions of Patient Non-Adherence on Educational Attainment and Social and Cultural Capital (N=81)**

	Model 1	Model 2
Constant	<b>.000</b> .500 (1.995)	<b>.000</b> 0.837 (0.560)
Educational Attainment	<b>-.240*</b> 0.160 (0.073)	<b>-.151</b> -0.125 (0.083)
Social Support		<b>-0.122</b> 0.009 (0.009)
Confidence in Institutions		<b>0.039</b> 0.005 (0.017)
Comfort with Authority Figures		<b>0.083</b> 0.083 (0.126)
Leisure Activities		<b>-0.027</b> -0.028 (0.135)
Social Capital		<b>-0.051</b> -0.004 (0.010)
R <sup>2</sup>	.240	.300
Adjusted R <sup>2</sup>	.057	.090

\*p<.05; \*\*p<.01; \*\*\*p<.001 for two-tailed test

First number reported in bold are the standardized coefficients, the second number are the unstandardized coefficients, and the number in parentheses are the standard errors.

**Table 9: Regressions of Patient Non-Adherence on TSEI and Social and Cultural Capital (N=81)**

	Model 1	Model 2
Constant	<b>.000</b> .750 (1.995)	<b>.000</b> .0127 (0.605)
TSEI scores	<b>-.280*</b> -0.020 (0.008)	<b>-0.245*</b> -0.018 (0.008)
Social Support		<b>-0.137</b> -0.010 (0.009)
Confidence in Institutions		<b>0.014</b> 0.002 (0.002)
Comfort with Authority Figures		<b>0.097</b> 0.096 (0.124)
Leisure Activities		<b>-0.026</b> -0.027 (0.130)
Social Capital		<b>-0.049</b> -0.004 (0.010)
R <sup>2</sup>	.280	.341
Adjusted R <sup>2</sup>	.078	.116

\*p<.05; \*\*p<.01; \*\*\*p<.001 for two-tailed test

First number reported in bold are the standardized coefficients, the second number are the unstandardized coefficients, and the number in parentheses are the standard errors.

Table 10 shows correlations between psychological variables and non-adherence. Self-efficacy has a moderate, negative association with non-adherence (-.35\*\*), while depression has a moderate, positive association with non-adherence (.35\*\*). Self-efficacy and depression have a moderate, negative association as well (-.50\*\*\*). Locus of control (-.22) and reactance measures (-.08) and (-.07) are not statistically significant.



**Table 10. Correlations between Non-Adherence and Psychological Variables**

	Education level	TSEI	Locus of control	Craving	Annoyance	Depression	Self-efficacy
Non-adherence	-.240*	-.280*	-.216	-.073	-.079	.346**	-.350**
N=	82	82	73	82	82	82	82

When non-adherence is regressed against the measures of SES and the psychological variables (Tables 11 and 12), self-efficacy remains significant while the other psychological variables are non-significant. While depression and non-adherence are correlated (-.35), when included in the model with self-efficacy that original association between depression and non-adherence is washed away. Both educational attainment and TSEI remain significant predictors of non-adherence with psychological controls.

### **Family Background**

One of the central features of Bourdieu's theory of cultural reproduction is that the family and the home life of individuals determines to a great extent individuals' capabilities in achieving status. With this in mind, we use both father and mother's SES (both educational attainment and TSEI scores) to determine if the benefit of high education is a product of that upbringing rather than the capability of that individual.

Results using the individual's education and father's and mother's education are shown in tables 13 and 14. As shown in models 1 and 2 in Table 13, father's education washes away the effect of individuals' education. In Table 14 on the other hand, when using TSEI as a measure of SES, individual's TSEI remains the important predictor of adherence while father's TSEI is non-significant. In both cases, mother's SES is not a predictor of adherence. Also in both models, smoking predicts non-adherence.

**Table 11: Regressions of Educational Attainment and Psychological Variables with Patient Non-Adherence(N=73)**

	Model 1	Model 2
Constant	<b>.000</b> .500 (1.995)	<b>.000</b> 2.161 (0.716)
Educational Attainment	<b>-.240*</b> -0.160 (0.073)	<b>-.245*</b> -0.146 (0.060)
Self-Efficacy		<b>-0.419*</b> -0.009 (0.025)
Depression		<b>0.115</b> 0.005 (0.018)
Locus of Control		<b>-0.153</b> 0.083 (0.217)
Annoyed When Behavior is Limited		<b>-0.152</b> -0.028 (0.046)
Craves Things one Can't Have		<b>0.184</b> -0.004 (0.116)
R <sup>2</sup>	.240	.352
Adjusted R <sup>2</sup>	.057	.293

\*p<.05; \*\*p<.01; \*\*\*p<.001 for two-tailed test

First number reported are the standardized coefficients, the second number are the unstandardized coefficients, and the number in parentheses are the standard errors.

**Table 12. Regressions of Patient Non-Adherence on TSEI and Psychological Variables (N=73)**

	Model 1	Model 2
Constant	<b>0.00</b>	<b>0.00</b>
	0.75	2.03
	-1.995	-0.721
TSEI Scores	<b>-0.280*</b>	<b>-0.208*</b>
	-0.02	-0.146
	-0.008	-0.007
Self-Efficacy		<b>0.436***</b>
		-0.094
		-0.026
Depression		<b>0.116</b>
		0.017
		-0.018
Locus of Control		<b>-0.094</b>
		-0.195
		-0.224
Annoyed When Behavior is Limited		<b>-0.128</b>
		-0.057
		-0.046
Craves Things one Can't Have		<b>0.175</b>
		0.188
		-0.118
R <sup>2</sup>	0.28	0.333
Adjusted R <sup>2</sup>	0.078	0.273

\*p<.05; \*\*p<.01; \*\*\*p<.001 for two-tailed test

First number reported are the standardized coefficients, the second number are the unstandardized coefficients, and the number in parentheses are the standard errors.

**Table 13. Regressions of Self-Reported Health on TSEI and Father's TSEI with Important Predictor Variables (N=81)**

	Model 1	Model 2
Constant	<b>.000</b> 4.09 (0.594)	<b>.000</b> 5.573 (0.882)
TSEI	<b>-0.083</b> -0.009 (0.013)	<b>-0.218*</b> -0.024 (0.010)
Father's TSEI	<b>0.216</b> 0.025 (0.013)	<b>0.117</b> 0.013 (0.010)
Non-Adherence		<b>0.368***</b> -0.555 (0.150)
Self-Efficacy		<b>0.171</b> 0.061 (0.037)
Non-Smoker		<b>0.366***</b> -1.378 (0.341)
Depression		<b>-0.319**</b> -0.076 0.025
R <sup>2</sup>	.046	.456
Adjusted R <sup>2</sup>	.022	.411

\*p<.05; \*\*p<.01; \*\*\*p<.001 for two-tailed test

First number reported are the standardized coefficients, the second number are the unstandardized coefficients, and the number in parentheses are the standard errors.

**Table 14. Regressions of Patient Non-Adherence on TSEI and Family TSEI with Important Predictor Variables (N=73)**

	Model 1	Model 2
Constant	<b>.000</b> 2.265 (0.492)	<b>.000</b> 2.347 (0.520)
TSEI Scores	<b>-0.272**</b> -0.020 (0.007)	<b>0.271*</b> -0.020 (0.008)
TSEI for father		<b>-0.127</b> -0.009 (0.011)
TSEI for mother		<b>0.070</b> 0.004 (0.009)
Self-Efficacy	<b>-0.303**</b> -0.071 (0.024)	<b>0.279*</b> -0.066 (0.025)
Smoker	<b>-0.190</b> -0.475 (0.255)	<b>-0.194</b> -0.483 (0.259)
R <sup>2</sup>	.280	.333
Adjusted R <sup>2</sup>	.078	.273

\*p<.05; \*\*p<.01; \*\*\*p<.001 for two-tailed test

First number reported are the standardized coefficients, the second number are the unstandardized coefficients, and the number in parentheses are the standard errors.

**Table 15: Regressions of Education and with Father's Education and Important Predictor Variables with Self-Reported Health (N=81)**

	Model 1	Model 2
Constant	<b>.000</b> 4.068 (0.409)	<b>.000</b> 4.868 (0.803)
Education	<b>-0.049</b> -0.050 (0.119)	<b>-0.113</b> -0.116 (0.097)
Father's Education	<b>0.294</b> 0.327 (0.128)	<b>0.191</b> 0.209 (0.110)
Non-Adherence		<b>-0.285**</b> -0.430 (0.157)
Self-Efficacy		<b>0.186</b> 0.066 (0.037)
Non-Smoker		<b>-0.334***</b> -1.259 (0.350)
Depression		<b>-0.316**</b> -0.076 0.025
R <sup>2</sup>	.079	.440
Adjusted R <sup>2</sup>	.055	.394

\*p<.05; \*\*p<.01; \*\*\*p<.001 for two-tailed test

First number reported are the standardized coefficients, the second number are the unstandardized coefficients, and the number in parentheses are the standard errors.

**Table 16: Regressions of TSEI and with Father's TSEI and Important Predictor Variables with Self-Reported Health (N=81)**

	Model 1	Model 2
Constant	<b>0.00</b>	<b>0.00</b>
	4.09	5.573
	-0.594	-0.882
TSEI	<b>-0.083</b>	<b>-0.218*</b>
	-0.009	-0.024
	-0.013	-0.01
Father's TSEI	<b>0.216†</b>	<b>0.117</b>
	0.025	0.013
	-0.013	-0.01
Non-Adherence		<b>-0.368***</b>
		-0.555
		-0.15
Self-Efficacy		<b>0.171</b>
		0.061
		-0.037
Smoker		<b>-0.366***</b>
		-1.378
		-0.341
Depression		<b>-0.319**</b>
		-0.076
		0.025
R <sup>2</sup>	0.046	0.456
Adjusted R <sup>2</sup>	0.022	0.411

†p<.10; \*p<.05; \*\*p<.01; \*\*\*p<.001 for two-tailed test

For each variable, the first number reported is the standardized coefficient, the second number is the unstandardized coefficient, and the number in parentheses is the standard error.

Tables 15 and 16 show how SES and important variables predict self-reported health. Without these controls, there is no relationship between an individual's SES and self-reported health. However, looking at the full models we see that measures of SES show a *negative* impact of SES on health. Similar to the models that predict non-adherence, father's education washes away the effect of individual's education, and father's TSEI does not wash away the effect of the individual's TSEI. As predicted, both smoking and depression are significant predictors of poor health.

## **Discussion**

The main goal of this analysis was to attempt to explain why SES and health are associated. As stated earlier, hemodialysis patients are an excellent population in which to discern these disparities because economic factors are mostly controlled for. By understanding the factors determining which patients follow orders and which patients do not would make clearer why the relationship between SES and health persists. Following Smith and Goldman's (2002) argument that patient adherence is central to explaining the SES/health gradient, a series of statistical analyses were conducted not only to explore that phenomenon but also to fully describe important factors that lead to good patients and also good health.

The major factors in the present study that lead to respondents being non-adherent are low SES, smoking, and low self-efficacy. As predicted, sociological variables such as social support, social capital and cultural capital are correlated with SES (particularly educational attainment), although these variables do not significantly reduce the relationship between SES and non-adherence. In terms of hemodialysis, having beneficial social connections, having a supportive environment, and participating in high culture activities (or strategies of "distinction") do not determine good patient management. Psychological and cognitive factors (such as self-efficacy) also play a significant role in patient adherence, and depression is a major predictor of patient self-reported health. Demographic variables such as gender, age, or ethnicity do not predict non-adherence. Smokers are more likely to be non-adherent and less healthy than non-smokers.



Somewhat surprising is the finding that social support does not predict patient adherence (in contrast to previous studies), although it is weakly correlated with self-reported health. The item used to measure social support seemed to be confusing to patients and there were quite a few missing values. While the item is a standard measure - it consists of five questions with three dimensions apiece - is possible that respondents experienced some fatigue with the question. Looking at individual responses on questionnaires, there are many contradictory and unlikely answers, so it is prudent to be skeptical of this measure. Social Support is correlated with other measures of cultural and social capital (and with SES), but neither of the dependent variables. A different measure of social support in a subsequent study is certainly warranted.

Despite a few studies that have shown correlations between non-adherence and male gender, there is no relationship here. Looking at the results of a simple table however finds that 7 out of the 10 least adherent patients are men (opposed to the fact that they only make up 56% of the sample). The ethnographic chapter deals with the gender issue more specifically.

Regardless of the finding that sociological variables (social and cultural capital, comfort in social situations, confidence in institutions) do not predict adherence, a few observations are still in order. First, the measure of cultural capital I use only entail one aspect of the concept. Shim's conceptualization of cultural health capital includes self-surveillance, self-discipline, an instrumental attitude toward the body, and a sense of mastery over one's health. It is still possible to develop some measure that would capture the self-surveillance of health and how it might mediate this relationship between SES and adherence.

The most noteworthy finding in the analysis is the father's education washes away the effect of respondent's education when predicting non-adherence, leading to the conclusion that having an educated father is more important than one's own self being educated. Something is passed from an educated father to the children which makes them good patients regardless of their own education. This does not hold true for mother's education, which could simply be the result of the demographic characteristic of the sample. Half of the respondents in this study are over the age of 60, and grew up in a time where women typically did not go to college. It would be expected that the effects of mother's education would be much stronger as respondent's age decreases, but there are so few young respondents in the study that it is not possible with the data to get a clear picture of the impact of mother's education on non-adherence.

By contrast, while using TSEI scores to predict non-adherence, individual's TSEI stays significant while father's TSEI does not. One could interpret these results as a function of the underlying phenomena that both education and occupation aspire to measure. Education, or being educated, reflects in many ways a family's value and capability of sending children to college. Coinciding with that is a deeper understanding of how the intricacies of life operate, and an ability to approach problems with a detached, rational perspective. Having a father with this approach to life would transmit an appreciation for seeing things in this way, while also providing an example of dealing with problems. TSEI (or occupation), reflects one's more active capabilities in securing employment. In this sense, success in the job market and success in the dialysis unit go hand in hand. The inconsistent findings between using educational attainment and occupation as predictors of non-adherence is important in the sense that it lends further support to the notion that all possible measures of socioeconomic status should be used when conducting research on health outcomes.

One of the most surprising finding is that TSEI predicts poor self-reported health when important controls (self-efficacy, depression, non-adherence) are in the model. However, this result could be more of a function of how one perceives one's health during chronic illness, and how it is colored by one's socioeconomic background and occupation. It could be speculated that high-SES persons are more focused, concerned, and aware of their own health status as Shim argues (2010), and when something drastic happens to them physically that change is much more conscious to these individuals. Additionally, it would seem more apparent to those with higher-functioning jobs since they require so much energy and focus to manage them. Despite the impact of one's own SES on their health during dialysis, father's education in particular still predicts self-reported health. The role of family education is important in both predicting one's adherence to dialysis treatments and one's perception of their health.

This analysis raises many questions for further research, the most important question being what it is about having an educated father that leads to better outcomes. Also, with there being so few cases in the analysis in which the mother is the primary source of family advantage, we would expect the role of mother's education to be more prominent for younger patients and for those person's in the future as demographic changes continue. It would be strange to see that only father's education has that impact and mother's education does not. The question of why early home life matters for both adherence and health will be a major focus of the semi-structured interviews in the proceeding chapter.

## Chapter 5: Qualitative Results

This chapter consists of an analysis of data gathered from 17 semi-structured interviews with hemodialysis patients. The purpose of the interviews is to provide a better understanding of the results from the statistical analysis. As shown in the previous chapter, occupational status and father's education are important predictors of non-adherence. While it was hypothesized that social and cultural capital were intervening variables between SES and adherence, the data do not show that to be the case, and there is limited evidence that cultural health capital moderates the relationship between SES and health.

In terms of the two major findings from the quantitative analysis, a few points worth are noting. A sizeable literature exists dealing with the positive association between occupation and health, and this relationship is mostly explained by the fact that those with better and more prestigious jobs receive greater fulfillment from them, thus lead happier and healthier lives. Those with better jobs are, "more likely...to experience autonomy on the job and non-routine work, both of which increase psychological functioning and job satisfaction" (Ross and Wu 1995: 722). Poorer jobs are monotonous, offer less recognition for accomplishments and awards, and do not lead to self-fulfillment. Also, as noted in Chapter Two, Marxist scholars find better health outcomes for individuals who have more control, less repetition, and more decision making in their careers (Borrell et al. 2004; Schwalbe and Staples 1986).

While a number studies show a link between occupation and health - most notably starting with the publishing of the Black Report which reported graded mortality rate increases for each occupational category in the British economy (Townsend, Davidson and Whitehead 1992)) - little qualitative research exists on how occupational status leads to better health outcomes. The finding that TSEI scores predict adherence for hemodialysis patients raises some interesting questions about the social-psychological aspects of occupation and if they translate into hemodialysis maintenance.

The interviews focus on answering questions about linkages between high or low status occupations and if occupational status in any way influences patients in terms of self-management. Some of the respondents interviewed saw dialysis as a part-time job, and it would certainly make sense that those individuals who take their careers seriously would take dialysis just as seriously –

even more so. Moreover, those respondents who did have regular, relatively high status jobs previously in their lives or even during hemodialysis talked of the disruption their illness caused on their careers. For many middle-class people with careers, their jobs are a key source of their identities, and their sense of self (in a positive way most assuredly) is centered around being productive and responsible. Those respondents lacking that pride in occupation, or status in an occupation, struggled to find meaning in the mundane yet difficult task of managing their illness. These issues are discussed in detail in this chapter.

The more compelling finding from the statistical analysis is that individual educational attainment is not a predictor of adherence when father's education is controlled for. The consequences of this reality are substantial. First it suggests that being educated, and all of the theoretically obvious impacts it has on individuals (learning skills, developing an instrumental attitude, organizing one's life, general learned effectiveness) are not the things that makes a patient adherent with their medicinal regimen. Second, it implies that having an educated father provides something specific to the child that matters for handling difficult health situations<sup>9</sup>. What that "something specific" thing is raises some interesting questions for research.

Could the relationship between father's education and patient's adherence be a direct effect? In this case, the father (or mother possibly) - due to learned effectiveness, instrumental attitudes, and the like - would teach their children a set of skills that either directly contribute to healthier behaviors or like-minded general skills that would have positive impact on their children's health behaviors. This notion is theoretically related to the concept of human capital, or skills and abilities that one attains as an investment in the future. According to Becker (2009), families invest their children with skills and abilities as a means to secure for their children a successful future. Health behaviors would be a direct outcomes or a consequence of this investment. Questions in the semi-structured interviews assess this hypothesis.

A second possible explanation of the relationship between father's education and adherence may have to do with the family structure itself. An educated parent or parents, in the time period in which many of the respondents were children (1930's – 1960's), is most reasonably a proxy for a stable, healthy home environment in which love and care are in abundance. One of the central themes of the life course perspective presupposes that growing up in a stable, loving

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<sup>9</sup> The question of mother's education is still not answered here. A better sample is certainly needed to ascertain this finding.

family has a positive consequence throughout one's life. In this case the impact of father's education does not directly operate through the transference of skills and abilities related to self-care, but rather through installing an attitude in the person so that those individuals would care deeply about their health, care about how others are affected by poor health, and seek to live the healthiest lives possible. Questions in the semi-structured interviews are focused on understanding childhood stability, enrichment, and care. In general, the major themes gleaned from the interviews suggest the latter idea to be more relevant here - that direct skills for dealing with health issues were not passed on but rather individuals with stable and enriching homes had positive attitudes toward themselves as people and their prospects for maintaining their health.

Last, the link between father's education and adherence may be the result of cognitive ability. In this sense, having higher levels of education is associated with higher intelligence, a trait which is passed on to children who then have better cognitive skills to deal with their treatment and illness. There are a growing number of studies that attempt to establish links between intelligence and health, many with mixed results. Whatever cognitive ability's effect on adherence is, it cannot be assessed in this study.

In summary, the following analysis revolves around two central themes: the role a respondent's occupation or occupational identity influences the way these respondents approach their illness; and the impact their father, and more generally their childhood lives, influences how patients deal with ESRD. A number of secondary themes are discussed in relation to occupation and father's education in relation to childhood. These include approaches to treatment, strategies for dealing with food and drinking restriction, how one deals with difficult situations, relationships to caregivers, and general worldview.

### **Occupational Identity and Illness Identity**

As reported earlier, occupational status as measured by TSEI scores, is a predictor of adherence with treatment. Responses from subjects during interviews provide some clues to why this is the case. Respondents who have or had "careers," and who understand their identity in terms of that career, see hemodialysis as a disruption of that career, but they are not redefined by their illness. The focus for these individuals is on managing to balance their occupations (from which

they receive a sense of accomplishment and purpose) and their illness. One gets the sense that individuals with formal occupations envision themselves as important to their families, the community, and the society in which they live, and their approach to their illness acknowledges their importance. More simply put, they enjoy and get satisfaction from their careers and that enjoyment or pride carries over to how they approach their health and their illness.

Roberta (white, female), for instance, in her early 70's who is a retired social worker and an administrator, sees dialysis as an annoyance rather than a defining obstacle. "The most difficult is it's like a part-time job. I spend a lot of time here. You sit and like you said, I read. I have days on the sofa. It's a waste of time... I'd rather, actually, be working. I did not want to quit work, but I gave up the stress and all." She laments the fact that she had to give up her career, and wants the structure back.

Despite Roberta's insistence that she was not a good patient, and is a self-confessed "Pepsi addict<sup>10</sup>," much of the evidence suggests that she is only a minor non-complier. She would not dare miss a treatment, and has survived 11 years as a patient and looks very healthy and vibrant. While she claimed at first that she doesn't "pay attention at all" to her diet, she later described specific strategies to deal with her illness. "When I get a craving for orange juice, I used to take a small glass of orange juice and that would end the craving. Now what I've been doing is buying tangerines, and they're the little ones. So I have one every day or every other day, and I don't have to drink the orange juice, which is worse than the orange." She is also very aware of how much potassium bananas have and is scared of having them.

Harold (white, male), a lawyer in his mid-60s who recently had a kidney transplant, discusses how he managed to maintain his practice despite his illness and even some of his doctor's advice. "I would have any number of doctors say, "What the hell are you working for? You don't want to just put in for your disability?" But as long as I was capable of getting here and generating some revenue, keep going." Of course his practice has taken a financial hit, but Harold still sees his illness as a hindrance rather than an ending. "Well, we've had to cut back expenditures at home, expenditures here. You just make do with what you can. Right now, we're covered, but I don't think I'm going to get back to the plateau of earnings that I had pre-dialysis, simply because a lot of those clients have scattered to the four winds." Although stressed by the rigors of being a lawyer, there is definitely a sense that he loves his job. "It was fun. Yeah. You get yourself involved in

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<sup>10</sup> Pepsi is high in phosphorous.

some dramatic litigation or dramatic defense of someone, it's just fun.” Harold was a model patient before his transplant who, with the help of his wife, maintained a strict diet and fluid maintenance and never missed a treatment.

Bonnie (white, female) in her late 50’s, worked as a radiation technician treating cancer patients for 20 years, a job she loved doing. “A typical day was very busy. We were always short staffed, and I was very good with the patients. I mean, they loved me. I had no problems with most of the patients, and I treated thousands and thousands each year. It was just something that I liked.” She was pursuing her masters in health administration when she got sick, and never finished her degree. She believes that she could still work, but has no interest working in health care any longer for two reasons. First, she disagrees with the way modern medicine is practiced. She loved her job as a technician since she was great with her patients, but was not popular among her superiors since she treated her patients first and did her administrative duties second. Second, Bonnie would have a very hard time separating her two worlds now because she is a patient dealing with issues from that side, and would have distancing herself as an administrator. “Yeah, there's a lot of bureaucracy. I was thinking of doing like health care administration, like a nursing home or something like that, but I don't even know if I'd want to see that every day.”

With the type of background in healthcare it is no wonder why Bonnie is a very good patient and looks and feels well. She is meticulous about checking her blood pressure which is an issue due to her underlying disease. She has developed specific strategies for maintaining fluid and diet restrictions, and never misses a treatment. She is hopeful about getting a kidney transplant and is currently waiting for one.

Eddie (white, male) in his mid-70’s (who looks about 55), is a retired hairdresser who owned three hairdresser shops. His father was a barber, but Eddie thought that too simple of a career. While he liked cutting hair, he found the challenge of dealing with women on a daily basis more worthwhile (and profitable). He describes an occupation with a great degree control over his own labor and the enjoyment he receives from dealing with his clients. “You always find — there's always somebody difficult to deal with, but you learn to deal with it. You become like a psychiatrist, more or less. So you've got to read their mind, and you've got to see where they're coming from, which direction they're coming, and you have to be aware to take care of the situation by whatever she's [unintelligible] before. I never had no problem with the women. I enjoyed it.” Eddie seems to have little trouble with his treatment regimen. He is fit, vibrant, and is feels very

good on his days off. While the links between his happiness with his job and the way he deals with treatment is not clear, his attitude is quite positive, and he does not struggle with the day to day issues of hemodialysis that some patients struggle with.

At first it seems somewhat mechanical to make a direct link between occupational status and adherence, but looking at these individuals in general there is a sense that they are happy people, and that they think positively about their illness and their lives in general. Attaining a job that requires creativity, inspires a sense of passion, and has a good deal of autonomy reflects an underlying sense of efficacy that may have links to health behaviors as well.

While the respondents described above had stable, well-paying, and meaningful careers, many other patients had jobs throughout their lives but did not have the type of “careers” that the respondents described above did. A number of patients with less defined “careers” tended to be the type of patient that struggled a bit more with aspects of their treatment. Not that these individuals were poor by any stretch (many were very comfortable financially), but they chose employment as a means to an end, rather than a career coupled with identity.

Tony for instance (Hispanic, male, 45), had been a manufacturing supervisor for 15 years until his kidney failure and his need to start dialysis cost him his job. While his job was stable while healthy, his company would not work around Tony’s new schedule and he was forced to go on disability. With a wife and four children, Tony is not only devastated because of the loss of his income, but also because his identity of being the boss at work clearly affects him. “It’s just with this, because all my life, I was a supervisor. So I was the guy, I could make a decision right there, boom, and stick to it and follow through. But this has really really turned my life inside out. Like I said, sometimes I get up, I say, ‘I don’t want to go there.’ And then when I come here, I’m like the youngest guy here. Everybody else here is older than me.”

. Not only does his wife have to work (with which he clearly is very uncomfortable), he seems to struggle heavily with the fact that their children do not have a strong, primary breadwinner in the household with him being the head. Tony grew up very poor in Puerto Rico, and was raised by his grandparents. He has very high expectations of what his social role should be in terms of his wife and family.

The pressure of not being live up to that expectation has led to pretty severe depression:

Interviewer: What's the most difficult part of being on hemodialysis?



Tony: I don't like coming here. I get very depressed. Tuesdays, Thursdays, and Saturdays are my worst days of the week. From the minute I get up in the morning, I get moody. In the beginning, I was depressed. They have to give me pills for the depression. I couldn't handle it. The day they told me, I cried like a baby.

My wife — my son is more positive — but I was like, "I don't want to do this." I got very depressed. They gave me pills for the depression. Then after that I just, I said, "I'm not going to be depressed. I'm going to try and deal with it." But now, because of all the problems they've had, I'm not an easy guy for them to do this to. So from the minute I get on up Tuesdays, Thursdays, and Saturdays, I'm already — pressure.

This unhappiness clearly has affected his compliance behavior. Since being a young adult, Tony drank Malta (a malted non-alcoholic beverage), and still continues that:

I don't follow it because, like I told my wife, I'm from Puerto Rico. There are certain drinks in Puerto Rico that I used to drink a lot, even though I'm not supposed to, but like I said, it all comes down, because I was never taught to take care of my diabetes, so I would eat and drink whatever I wanted to. So even now, I told my wife, she goes, "Oh, don't drink this or don't drink that." And I changed a lot of that because there are some things that I'm going to drink it, whether it's going to kill me or not, I'm going to drink it. Why? Because I was raised with that.

We have this drink called [Malta]. It's a malt beverage, but it comes in a glass bottle. I love that. Every day I've got to have at least two. Now, that's liquid that I'm not really supposed to, because I could only take so much. But I'm thinking, well, I'm drinking my cranberry juice every day, so that should be cleaning something out. And I have a struggle with that. The fluid restriction kills me because I'll drink instead of eating.

I'd rather have something to drink than something to eat. So it's very, very, very tough for me to do that. So even though my wife tells me or they tell me, "Oh, you've got to watch the liquids. You've got to watch the fluids." There are some days where I'm just, you know what, I feel like having a Malta and then I have a Malta. If ten minutes later, even though I haven't gone to the bathroom, I feel like having another one, then I'll have another one. So that's something that I'm still struggling with.

Tony's drinking seems to be reactance behavior, a situation in which a person's agency is taken away (in this case, Tony's ability to provide for his family), and his non-adherence to fluid restriction as an attempt to reclaim that agency. This non-adherence is linked a sense of fatalism within Tony:

Because I always told my wife that [we] can never die. But some days, I'll get up and I'll be like, "Well, this is my last year, so I'm going to try enjoy life." And I've actually told my wife, I said, "Prepare yourself to learn to live a life without me." Because sometimes I feel like I can't make it another day. So I put her in that — and also, we've been married for 14 years, and it's tough. So some days, I'm just like, "Oh, I'll make it. I'll make it."

So I'm caught in that struggle. I have this struggle.

Interviewer: Is it sometimes that you just get down — it's almost like you don't feel like living?

Tony: Yeah.

Mike (white, male) also 45 years of age, struggled with diabetes for most of his life until it led to kidney failure and the loss of his sight during the past few years. While he was a good student in high school, the discipline instilled at his parent's home seemed to abandon him in college where he eventually became addicted to alcohol. Mike never finished his four-year degree, and his alcoholism plagued him into his mid-twenties when he was involved in a serious car crash that, he believes, exacerbated his diabetes. During the course of his life he's worked in sales, as a financial advisor, as a collections officer at the IRS (a job that he was eventually fired from for excessive lateness), and finally as a machine operator at Newsday. He had to quit his job at Newsday due to the loss of his eyesight, and went on disability.

Mike never seemed to find a stable, enjoyable job. He worked at the IRS for 14 years, and eventually started to dislike the pressure.

Mike: It was a collections job. I was on the phones constantly. And it was high pressure at the end.

Interviewer: Did the department itself change?

Mike: When I started there, I was a typical government paper-pusher. You had a pile of papers and you pushed the papers to the side if you didn't wanna [unintelligible]. You [were] working with your manager at the end of the week or so. You could spend an hour with the manager at the end of the week and settle the issues. But the collections and trying to deal with it on the phone with the [customer], you couldn't push 'em to the side.

Mike started having difficulty with the job due to his diabetes as well since he was very inactive and at a lot of fast food. In the end he simply did not want to be there.

While Mike is not a terrible patient per se, he does not have the carefully measured approach to his health and illness that the more adherent patients do. He is one of the many patients whose undisciplined lifestyle led to his kidney failure in the first place, and that non-adherence (and the attitude toward his own health), is evident as a dialysis patient. Having had trouble with phosphorous and potassium levels in the past, he has skipped treatments at times. When asked about his medications, Mike is somewhat unclear about the name of his medications and what they each are for. While at the moment he is doing OK as a patient, it is hard not to see how his past behavior has caught up to him. Mike seems very lethargic, disinterested, and depressed.

Thomas (black, male), in his mid to late 60s, has been a dialysis patient on and off since 1990. He has had three kidney transplants that had lasted a total of 11 years. The first time Thomas had to receive dialysis treatments he used peritoneal dialysis, and struggled heavily with it. He would simply skip a lot of his exchanges to go out fishing, which almost cost him his life. Thomas has spent a lot of time in the hospital due to his non-adherence and he feels very lucky to still be alive.

Thomas has struggled with his phosphorous so much that his doctors had to perform a Parathyroidectomy<sup>11</sup>. During his time as a patient, Thomas has consistently been a poor patient. Eating salty food led him to problems with his fluids. He refused to give up the food that he enjoyed eating until he got so sick that he would end up in the hospital. As with some patients who have a history of poor adherence (the ones that survive), Thomas has learned to control his behavior more recently. “Now, I’m older, and I can’t be playing around. Because I had a heart attack, and I had a quadruple bypass. I had another bypass. I ain’t playing around no more, you know? I mean I cheat with the ice cream sometimes, but I like butter pecan. I like [unintelligible]. I can’t help it sometimes. Stuff like that. But with the fluids and stuff, I kind of control it. I know how much I can handle.”

Thomas has worked many menial jobs throughout his life. He did finish his high school diploma, but turned down an offer to play college football at Albany State.

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<sup>11</sup> This procedure is needed because the parathyroid hormone excreted by this gland causes severe bone loss and pain. The excessive hormone is a direct result of having too much phosphorous in the bloodstream, a symptom of poor dietary adherence.

Interviewer: You finished high school?

Thomas: Oh yeah. I was trying to go to college. Albany wanted me to play football for them, Albany State. The coach called up for me. After I thought about it, I said, "No, I don't want [unintelligible] football." Then I was supposed to go upstate somewhere to — I can't think of the name of it now — and I went there with transcripts and everything, and they said, "Well, if you want to come here, you've got to go through an extra year of work release or whatever it was, and then you had your four years." I said, "No, man, I ain't going no five years of college." So I didn't go.

Thomas turned down a great opportunity for a seemingly petty reason, not knowing the possible positive benefits that could have had on his life. Instead he ended up working laborer and construction jobs before getting a job with the highway department, where he worked for almost 20 years until he was forced to retire due to his illness.

Barbara, sixty-three, also turned down college (with some regret), although in her case it was because she focused on marriage and her children. Her husband left her after some time, and she was left to raise the children pretty much on her own without any financial support. She made extra money by being a seamstress, working as a maid for a bus company and taking care of the elderly.

While Barbara does not have any major problems with the medical regimen (due to the fact that she does not really have an appetite anymore), her previous behavior (an addiction to diet pills), exacerbated her diabetes which led to kidney failure. She is very depressed, and hates coming to treatments. She seems to make light of very serious situations in her past (a violent episode where she says she threw a butcher knife at her husband) and has other heartbreaking stories. During the course of the interview, she consistently steered the conversation away from anything having to do with herself and instead focused on her family and how well they were doing.

While it is difficult to provide direct links between occupation and non-adherence, something certainly comes across during the interview that makes one think that occupation has a larger meaning than people who conduct health disparities research realize. The individuals I interviewed who had stable and fulfilling careers seemed very confident about handling dialysis, had a positive attitude about their futures, and took specific, strategic steps to manage their health while being a hemodialysis patient. Many of the respondents without a structured career, on the

other hand, seemed trapped in a situation outside of their control. These respondents used the word “struggle” often, implying that they were constrained by circumstances.

### **Father’s Education, Childhood Milieu, and Family Stability**

In this section, the relationship between father’s education and adherence is assessed. As stated earlier, a direct effect of transferring skills from father (or both parents) to their children is not apparent from the interviews. In reality, there are two major themes that do emerge from individuals the interviews. First, respondents from families with educated parents are - similar to the previous section that focused on occupation – are positive about their health and confident about their ability to deal with difficult situations. Secondly, it very much is evident that having an educated father is really a proxy for a stable, nurturing, and enriching childhood. The patients who lacked that stability in early childhood were much more likely to struggle with treatment, and they exhibited a worldview that was generally negative, and in some cases they thought the world was against them.

Faye (white, female), the daughter of a garment factory owner and housewife, describes a happy childhood. “Yeah, it was a stable, happy family. Stable and we enjoyed company. We had family and we enjoyed family. It was really happy, very happy. I had no problems.” She attributes her good behavior and habits throughout her life to her parents and the education she got at Catholic school. Faye’s father, a carpenter from Italy, emigrated to the U.S. and eventually became a wealthy businessman. While not formerly educated, he certainly made sure his daughter went to the best school he could afford, and she was able to go to college and become a school teacher. Faye is very adherent, and never has trouble with any aspects of her treatment, and sees the best of the situation:

Faye: I come here, and this is my second home. That's how I feel. I come three days a week.

Interviewer: I could tell, you have good relationships with the people here.

Faye: Oh yes. I love them all. We joke around and, in fact, we play [iPod], one of the nurses and me, we have a good relationship.

It is simply something she must do to live longer. In all, Fay is interested in living a good life. She left her first husband because he cheated on her, and in many ways this is an aspect of her independence and confidence. Seeing other patients who struggle, she argues that they just cannot accept their fate.

Susan (white, female) is 68, and is the daughter of an engineer and a homemaker. Her father was a World War II veteran and received his Bachelors of Science degree from a very good, private university. She credits her parents (besides her religious faith) with the capability to handle the difficulties of her illness:

Interviewer: Was there something about — if it's not religious — but there was something about what they taught you, in terms of values, that makes you the person that you are here, and that you're able to have this positive attitude towards things? Were you parents positive people in that way?

Susan: Yeah. They taught me not to sit around and do nothing. I was always out there gardening, even at my parent's house and doing jobs and I'd take care of my own clothes, do my own ironing. I was pretty independent, even back then.

Harold, the lawyer who received the kidney transplant, had a father that was constantly reading books.

Harold: Dad worked for what was then known as Linde Air, and his title was a [kneeling] furnace operator. Lindy made oxygen, nitrogen, things like that... That was the right job for him, because he as a prolific reader, and his job required him, they would load in a tank that has to be heat treated. So he had to set the gauges for the furnace that's doing the heat treating. Then he would periodically watch the gauges for eight hours. Well, I don't know how often he had to do, but every day he knocked off a book.

We had the complete works of Shakespeare at the house, and he was actually an actor locally at [Sumner now], and an [equity] card member, did studio arena.

While again not formally educated, for Harold's father education and enrichment was important for his children.

Harold: Well, insofar as we had all gone through St. Francis and high school and there was always an emphasis on books. "Read something." Because he was — the old man had a real good friendship with a guy who owned a bookstore. So he would make a weekly trek to the bookstore, and never paid a dime for anything he pulled off the shelf. He just brought it home and brought it back the next week to Dominic's store.

So those books got passed around, and everybody was very well read. Most had some college. I'm the only one who actually went beyond a bachelor's degree and got the JD.

There is a real sense that both Harold's mother and father felt that the focus on education would benefit their children.

Interviewer: So you don't think that was your parents influence on you and having that value, or it was just something that you felt was important?

Harold: Oh, I'm sure it was — they were significant contributing factors to my need to succeed, especially my mother, who would inquire every once in a while, "What are you reading this week? How's school?" She was very active in the school societies.

Roberta's father was well educated as well. She describes a somewhat idyllic and stable childhood, and then the subsequent stability of living near her parents as she got older:

Roberta: At home, when it was nice weather and the ice cream man would come about three o'clock, my father would be home, because he was an attorney, and he made his own hours, and my mother was a stay-at-home mom, and probably the worst cook in the world. She could make good chopped liver and a good turkey. That was it.

But everything — we all had dinner together every night. It was extremely rare that my father would be late. In the winter, he came home a little later, because the ice cream truck [unintelligible] so he didn't have to buy me ice cream or my older brothers. But I lived near them when I first got married and had a couple of kids.

Education was highly valued by her parents, and Roberta was consistently asked about how well she was performing in school during her adolescence. Even when Roberta did not do well in college during the first few years, her parents were insistent:

Roberta: Oh yeah. We were told we were going to college. We weren't asked. I didn't know I had a choice, and we all, my brother and I, went. My father said, "Norman, you're going to be an engineer. You're fantastic in math." My brother became a mathematician. He didn't know what to do with me, my father. I was the difficult child, but I had to go to college, and I went to a teaching school, [unintelligible]. It was amazing. It was so [unintelligible]. I actually flunked out after two years. I came home. "You're still going to college." And I went to Queens for some courses, and one of them I actually liked. I got an A in that one. He said, "You're doing this just [unintelligible]" I said, "No, I don't like being in school." Except for this one teacher.

While some of the best patients came from homes in which education was highly valued, other homes offered a degree of stability. While Bonnie's parents were not high status (her father a postal worker, her mother a homemaker), there was a sense of stability and care in the home. Bonnie's parents were proud that she went to college and succeeded, and she had their support throughout her life.

Alan (white, male), in his late 50's, did not have educated parents either, but home life was stable and relatively happy. When he was very young Alan discovered that he had a very rare liver disease that he has lived with throughout his life. By the time Alan was 45, that disease had caused his kidneys to shut down, and since then he has had two liver transplants and a kidney transplant. While not formally educated himself, Alan is very knowledgeable about his illness and the steps it takes to get another kidney transplant. He even subscribes to a transplantation magazine he reads every month. He is a very conscientious patient and knows exactly how to deal with the rigors of hemo-dialysis.

Alan's father was a Korean War veteran then went into construction, while his mother was a homemaker. "My mother and father stayed together forever. As the story goes, 'til death do us part. That's how that went." When asked how Alan dealt with the fact that he's had health problems his whole life, and how he has handled it, he cites his father's influence.

Interviewer: I was asking you about your attitude towards — I mean, even the fact that you dread it here and you dreaded your work and that, but you seem to be able to adapt to the situation. You forget about the terrible things and just don't dwell on it.



Alan: I learned [unintelligible] from my father. My father was a Korean war veteran, and he never harped on anything. He sort of made comments that — I'd be like, "Wow, dad, it's freezing out." He said, "You don't know what cold is." [unintelligible] never harped on the fact of what he did until later on in life when I actually asked him, sat down with him and listened to him.

Interviewer: Why, what was he talking about?

Alan: I'm saying he had a rough time over there. It wasn't a pleasure cruise. But they were all enlisted. They were there because they wanted to be there.

There was a certain reverence for his father when Alan mentioned him in the interview, and that closeness has been important to Alan in terms of approaching a difficult situation.

While patients with either educated fathers (or perhaps parents who valued education), and patients with stability in early life found dialysis challenging but necessary to deal with, patients without that early stability found the rigors of treatment overwhelming. Tony and Thomas, who were discussed earlier, both had troubled childhoods. Tony's parents abandoned him when he was six. Although Tony had very loving and caring grandparents, Tony still feels a lot of anger toward his birth parents, and is not in contact with them. Tony who also feels very strongly that no one in his family ever taught him or disciplined him to take care of his diabetes, still has resentment toward them.

Thomas was also raised by his grandmother, but in extreme poverty. His father was rarely around, and he does not mention his mother much in the interview. While Thomas mentioned a high degree of household discipline, his grandmother was not that concerned that Thomas skipped school often. "Go to school. My grandmother, she wouldn't say, "Get up and go to school" but she'd come up, "\*\*\*\*, are you going to school today?" So she said, "Are you?" "No, I ain't going today." Stuff like that, where she didn't really push it, push me. "Get up and go to school" she didn't say it like that. "Are you going to school today?" "No, grandma, I don't feel good." "All right, then you better stay in the bed." She babied me. It didn't help me. She babied me."

Abe's (white, male, 65) story is relevant here because although he himself became educated and successful, yet struggled with many aspects of his treatment. Abe went to prestigious universities for both his Bachelor's and Master's degrees. After his education, Abe then worked for intelligence agencies, consulting mostly on warfare, then switched to a career on Wall Street

again as a consultant and then a manager of a hedge fund. He continues to trade stocks and manage money today.

While Abe was born to two loving parents, his father passed when he was 10 years of age. He was very close with his father, while he had a somewhat distant relationship with his mother. He attributes his difficulties with both phosphorous and fluid control to the undisciplined home life he experienced as a young teen. Without his father around and a mother that was always working, Abe was never taught good habits in terms of eating and drinking.

### **Final Reflection**

While discussing some of the links between occupational attainment and adherence, it was somewhat difficult to make direct associations. However, underlying the theoretical construct “occupational attainment” is a reality that most assuredly reflect careers that provide a source of pride, enjoyment, and stability to people. Those characteristics, I argue, have implications for how dialysis patients deal with the difficulties of their illness.

An even more complex web to untangle obscures the reasons for just why father’s education and adherence are associated. Questions were originally developed to ascertain what participants believed they learned from their parents that helped them deal with the difficulty of dialysis. The original research questions were focused on skills and strategies that parents passed to their children that these individuals accessed to ensure a better, healthier life for themselves while having end-stage renal disease. What became clear during the course of the interviews is that there were not clearly defined skills or strategies that parents passed to their children, at least so far as the respondents remembered. What did emerge from these interviews was a general description of their childhood, in some cases positive, in some cases not so positive. Also what was evident was that many respondents were able to identify certain values or attitudes that their parents exhibited. In many cases, respondents saw these values or attitudes as guideposts for their own behavior, and strived to live up to them. Respondents who had trouble with aspects of their treatment were much less likely to discuss what they learned from their parents, and some indicated that they did not know their parents that well.

## Chapter 6: Ethnographic Results

This chapter recounts some of the experiences I have personally had with kidney failure and dialysis. One can consider this reflection *auto-ethnographic*, a type of social research that allows the researcher's subjectivity to be part of the analysis, rather than restricting subjectivity in typical social science research (Ellis 2004). The singular "I" is used quite often. While some auto-ethnographers reject that traditional methods of social inquiry (quantitative and qualitative data analysis) can ever express the "truth" of a social phenomenon, I would argue that each method reflects a different layer of reality and a different "truth."

I include this chapter in the project is that it is a good supplement to the quantitative data and qualitative data. The subjective perspective of experiencing dialysis first-hand provides insights into the physical and psychological requirements of treatment. Because it is a distinctively different life than most people face, including this narrative fills in the detail of what the surveys and interviews cannot. During qualitative interviews, people rarely open up enough to let themselves describe the emotional battle they have with this lifestyle. I have tried to be completely forthcoming about these experiences, with a rich description of them. Further, I have included this personal narrative into the project because it one of the few resources available that describes habitually non-compliant patients<sup>12</sup>. This is by no means a systematic analysis, nor should any firm conclusions be drawn it, but it does reflect public displays of non-compliance.

A few notes on the text are in order. First, there are no field notes. The time spent in dialysis happened almost entirely before the beginning of this project, and there was no systematic attempt to create an ethnographic field site at the dialysis unit. The writing of the chapter (excluding this short introduction) took place before the bulk of the data for this project was collected, which means that what is described is unbiased by results from the survey and interview data. The bulk of the narrative and the experiences that took place were from February 1998 through February 2000, and February 2006 and April 2010. Pseudonyms of people are used (other than my brother), and the dialysis units are not named. Second, the conclusions from what follows reinforce - but also contradict - some of the survey and interview data. One of the major issues that is not captured

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<sup>12</sup> For a full discussion of sample bias, see the methodology section in Chapter 3.

by either the quantitative and qualitative analyses is the outlier patient – the angry man. While some research has shown a relationship between being male and being non-compliant with treatment (Bame, Petersen and Wray 1993), no study has systematically looked at masculinity and hemodialysis compliance.

There are two themes in this chapter. The first involves the relatively small but important group of middle-aged (and to my perception) working class men who I consistently found to be defiant and antagonistic to the staff at the hemodialysis center. These men highlight the “bad” patients with whom staff must deal. Unfortunately, the reality of being a “bad” patient is all too real, and many of them (to the best of my knowledge) have died. The second theme I find to be relevant (and is also dealt with in the qualitative interview section of this work), is the approach one takes toward all aspects of having ESRD. One can be thoughtful, conscientious, positive, involved, self-monitoring and open to help, or one can feel trapped, helpless, untrusting, negative, and be in constant denial of the effect that one’s behavior has on their health.

### **Experiencing Hemodialysis**

When I was 13 years old (and my brother Steven was 15), we were both diagnosed with Alport’s Syndrome, a hereditary disease caused by mutations in collagen IV genes. Missing these genes prevents the production or assembly of the type IV collagen network, which is an important structural component of membranes in the kidneys, ears, and eyes. The disease typically affects males, while females are carriers of the disease on the X chromosome. Sufferers generally experience kidney failure in late teenage years or early adulthood. My brother Steven lost the use of his kidneys at 18 – I lost the use of mine at 20. I have some hearing loss as well.

We both took it in stride, as did my mother (who, incidentally, was the “cause” of our kidney failure since she is the carrier of the genetic mutation). We sometimes teased her about it. Although she’s never spoken about it, I suspect she feels some irrational guilt for what has happened to her two sons due to her imperfect genetic makeup. But nevertheless the three of us were not afraid, and we dealt with things as rationally as we could. The nephrologists told us that we would probably lose the function of our kidneys over the next few years, and that they would

do everything possible to prevent that loss. But the three of us knew that it was only a matter of time.

In 1993, Steven started peritoneal dialysis which uses the patient's peritoneum in the abdomen as a membrane across which fluids and dissolved substances (electrolytes, urea, glucose, albumin and other small molecules) are exchanged from the blood. One of the main advantages of peritoneal dialysis is that fluid and diet restrictions are minimal for the patient, much less of an issue than for hemodialysis patients (on which this study focuses). However, the responsibilities of self-care are very high, requiring either strict regimentation by the patient or the help of an additional caregiver.

My own stint on hemodialysis began in February of 1998 when I was 20 years old. During Holiday Recess from Binghamton University, I visited my nephrologist in Buffalo who, after looking at my blood work, informed me that I needed to start dialysis soon. I was initially shocked by the news, but it made sense since that past semester at school I had been feeling odd. I did not feel “sick” that semester, but a strange, deep cough had developed and in retrospect was a symptom of my kidney failure. I had a choice to make because I had a productive fall semester in my course work and I was finally starting to perform well as an undergrad. Because the spring semester of my third year of college was only weeks away, I did not want to destroy the momentum I had created for myself in school (especially after struggling my first two years). After some thought I told my father that I would start dialysis in Binghamton and go to school part time; although skeptical, he agreed.

### Treatment

Things were very rough at first. My nephrologist in Binghamton let my situation deteriorate too far before I began dialysis treatments in February. The surgery to create my dialysis access (where the blood is drawn during dialysis), was very unpleasant. The anesthetic used at first was fine, but I woke up with some 30 minutes left in the procedure (which typically takes about 2-3 hours). Not only was it uncomfortable to have people rearranging my arteries and veins while awake, but the toxins in my system had built to such a degree that I was shaking. After my father had dropped me off at my apartment that night, I lay in bed with massive pain in my arm (with nothing other than Tylenol to dull it) and the terrible tremors from being considerably toxic. It was simply the worst day I have ever lived.

The next day I was in the hospital early and my nephrologist was inserted a temporary catheter into my neck so I could start dialysis right away. Medical students looked on as the doctor forced and pushed plastic and metal through my heavily-muscled neck and shoulder. The catheter is typically inserted into the jugular. I distinctly remember the feeling I felt after leaving the hospital after my first treatment. I felt warm, hungry, and more alive and vibrant than I think I have ever felt, realizing for the first time how sick I really was before treatment.

My fistula took some six weeks to develop so I had to live with the 3-inch plastic catheter protruding from my neck. The nurses at dialysis started to use my fistula in early to mid-March. Before physicians remove the temporary catheter (which by this time I was dying to have out – mostly so I could shower<sup>13</sup>), they must make sure the fistula functions properly for a few treatments, as mine did. Shortly after my catheter was removed however, I infiltrated (where blood enters the surrounding tissue), and I could not have dialysis that day nor the next few days because of the severe swelling and pain in my arm. Skipping dialysis treatments is dangerous, but since I still had kidney function and was still urinating, the doctor said it was fine.

### Worries

Infiltrations are just one of the worries that patients with fistulas and graphs have to deal with from time to time. Infiltrations occur when the venous needle (the one going back into the body) is placed incorrectly and goes straight through and punctures the vein used for blood flow. When the machine starts, blood is forced into the surrounding tissue instead of the vein. The goal of enlarging a blood vessel through creation of a fistula or graph is to create sufficient blood flow in order to achieve maximum treatments results. Patients with arm accesses that work well typically can achieve a blood flow rate of 450 mL/min (milliliters per min), with some up to 500 mL/min. The higher the volume of blood that works through the membrane of the artificial kidney (or dialyzer), the better the dialysis a patient has. Another advantage of having a large vessel is that insertion of the needle is simpler for staff members. A small vessel increases the likelihood that the needle will puncture the wall of the artery and blood will rush into the surrounding tissue instead of the artery.

Depending on how much blood enters the surrounding tissue determines how bad the infiltration will be. A small amount will create a small bruise that may be sore for a few days. A

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<sup>13</sup> If water seeps into the entry site of the catheter an infection can develop easily.

larger infiltration will make a person's arm black and blue for at least a week and sometimes two weeks, and the likelihood is that the victim will miss dialysis time. During the six years on dialysis I infiltrated twice – the first time mentioned above, and a second time for about a split second when I warned the staff member I was infiltrated and she stopped the machine immediately. Whenever a nurse or tech starts the machine, I pay close attention to how my arm feels. If there were to be any stinging sensation whatsoever, there is an infiltration. I was being vigilant at the time of my second infiltration and I caught it immediately.

Being a good dialysis patient while undergoing treatment is about having awareness all the time – awareness about your body for the most part, but awareness of one's surroundings when they are undergoing treatment. If someone were to walk into a dialysis unit, you would find most patients asleep. I was scared half to death to fall asleep during a treatment.

I was extremely vigilant about keeping my left arm, where my needles were inserted, as stationary as possible. The experience of my first infiltration (in 1998) is still fresh in my mind and will continue to be for the rest of my life. Not only was it horribly painful, but the larger issue of keeping my arm as healthy as possible is still a focus of mine. After six years of using my left arm as a conduit for dialysis, the vessel walls have weakened, circulation is poor, and some nerve damage seems to have occurred. My arm bothers me from time to time, especially on rainy days.

Many patients move their arms (and their whole bodies) continuously during treatment (much to my horror). When the pressure of the blood flow in the arterial or the venous needles (blood coming into the machine and blood going out to the body respectively) is outside of normal parameters, the machine will alarm and automatically stop the blood flow. Patients who move their arms around cause their machines to alarm and their machines stop consistently. During a four hour treatment, a restless patient can make their machine alarm from needle pressures at least ten or more times.

My machine might alarm and stop once during a treatment. I would sometimes go weeks without my machine alarming. It was always a frightening experience when my machine would alarm and stop during a treatment. I suppose it was the unknown of what was happening since the alarm would go off while my arm was completely stable and unmoving. In most cases, the machine would alarm and stop because the parameters of the needle pressures needed to be readjusted, which is a very simple thing to fix and is accomplished by the nurse or tech punching a few buttons on the machine. Many times alarms would go off because of machine errors. These are almost

always harmless and it is just a matter of the staff fixing the error or moving a patient to another machine if the technical issue is severe enough.

There is, unfortunately, always a small chance that something has gone horribly wrong. Sometimes, a blood clot would begin to form in one of the small pressure chambers in the machine. Clots typically form when a patient is not given the necessary dose of blood thinners (such as heparin), during their treatment. Typically this is not a serious problem since it is highly unlikely that the clot would enter the patient's bloodstream. However, if the clot cannot be broken up or removed from the machine, the problem tends to get worse and worse as the treatment continues. Many times, especially if the clot occurred earlier in my treatment, the staff would have to set up an entirely new machine that could take 30 minutes to complete. However, a few times the clots were so bad (and not dealt with by the staff seriously enough) that there was no way to return the blood in the machine safely to my body. Patients are already anemic and the loss of half a pint of blood makes patients more anemic, leading to symptoms such as fatigue and general malaise and poor concentration on the mild side as well as palpitation, angina and heart failure as the anemia worsens.

Another reason the machine alarms is that there is air in the blood. The blood held in the tubes of the machine (and the bodies to which they are attached) are closed systems to air. From time to time though, air may enter the circulatory system of the tubing typically because of a leak. The reason why air in blood is a problem is that if enough air enters the bloodstream a gas bubble could block blood flow in veins. A gas bubble in the heart could stop the heart from beating and the patient would die from the air embolism. System safeguards make such an this almost impossible.

It was not uncommon for my machine to have air in blood alarms at the dialysis facility which I received treatment. When the alarm went off, either the nurse or tech would usually say what the alarm was for (or I would ask). An "air in blood" was an alarm that made me sweat heavily. I would scan the blood tubes for any bubbles of air and mention it to my nurse if I had seen one. Sometimes, it took time for the nurse or tech to fix the air-in-blood problem. As they would start the machine for a few seconds, then alarm and stop. Experience and skilled workers could usually fix the problem with one or two tries. For the inexperienced and unskilled, the alarms could go off for a half hour, and then my blood would begin to clot in the machine. A few times, this clotting would prevent returning my blood to my body, and I would end up losing a half pint.



While air in blood and clots are somewhat routine malfunctions of hemodialysis, rarely do they lead to severe cases where a patient's life is in danger. While clots and air in blood are typical machine malfunctions, generally the most routine situation where there *is* a serious danger is hypotension, when a patient's blood pressure drops too low, which tends to happen toward the end of treatment. Hypotension is caused by the rapid removal of fluid during treatment. Hypotension most commonly causes symptoms such as sweating, dizziness, shortness of breath, nausea – and, if not dealt with quickly, and depending on severity, loss of consciousness and death.

Strange occurrences happen during these episodes. In my personal experience, sweating was usually the first sign of the blood pressure drop. At the first hint of sweating, I would ask the nurse or tech to check my blood pressure (which was already being checked every 30 minutes). Most of the time, I would ask the nurse or tech to slow down the fluid removal rate from my body, which usually solved the problem. Further, I could be pushed back in a prone position in the recliner chairs in which all patients are given treatment. If I could feel the warmth and sweat from my body strongly, I would ask for 100-200 cc's of saline (salt water). On very rare occasions for me, the warmth and sweating would hit without warning. I remember getting very nauseous and vomiting twice during my six years of dialysis. Once, as I lay back warm and sweating, I felt a very strange and horrible feeling come over me, and my vision started to narrow and my world started to shrink. I can scarcely remember being more afraid in my life.

I was extremely vigilant concerning my blood pressure, especially during the last hour of treatment when hypotension is most likely to occur since most of the fluid has been removed. While the blood pressure cuff reports a low pressure, it only does so every 30 minutes. Therefore, many episodes of severe hypotension are missed because the patient's blood pressure had not been taken recently and these patients cannot detect the warning signs of low pressure. As mentioned earlier, many patients sleep during treatment, making the situation even more dangerous since a blood pressure drops as a response to sleep. At the same time, the patient is not aware of warning signs such as dizziness, fatigue, nausea and sweating.

For older patients, hypotension is a continuous problem. Their bodies are not equipped to deal with the rapid removal of fluid as younger patients are. Many times their systolic pressures could be in the 70's or 60's, and sometimes a diastolic could not be measured. Many, many times older patients lose consciousness, with some needing to be taken to the hospital. This is not an uncommon way to die for patients.

There was a tall, gaunt, middle-aged African-American man I remember distinctly. He never seemed in the best of health, but he always tried to charm the nurses with his raspy voice and charming smile. One of the techs told me he was a former drug user, but had beaten that battle only to end up with destroyed kidneys. He went into hypotension during a treatment. I thought he looked odd as they sat him up after cutting his treatment short. His face was pasty white, and his eyes were glassy. Some few hours before he had been his normal self, but after that episode he looked like a different person – and not a person that looked well. He did not respond to the questions the nurses asked of him, and soon the paramedics came. He died a few days later.

There are also dangerous situations where the machine does not alarm. For instance, needles have been known to dislodge themselves from a patient's access. If the arterial needle is dislodged the machine will automatically stop since the machine will be sucking air. However, if the venous needle is dislodged, the machine will simply keep pumping blood out through the needle onto wherever the needle is pointed. A simultaneous danger in this situation is that the needle hole where the needle was inserted in the patient is now exposed and un-clotted. Since the access is capable of creating a high blood flow, the amount of blood discharged from an un-clotted access is significant. Combined with the blood pouring from the dislodged needle, a continuously pumping machine, an unaware patient, and staff members otherwise occupied, this situation can get dangerous very quickly. This is a danger to others as well since an adjacent patient or nearby staff member may get showered with blood. I've seen this happen multiple times, and there have been other times where I've warned staff members while this was happening.

Some dangerous situations are impossible to predict at treatments. For instance, one of the techs had given notice to her supervisors that she was leaving her job at the facility. I was one of her patients on her last day, and she was visibly upset that she was leaving. I noticed that she was having trouble setting up my machine. Before treatment, the machine is "primed," where the tubes and chambers of the machine are filled with IV saline. When she had the machine primed, there was quite a bit of air bubbles in both the dialyzer and the tubes. I mentioned this to her and she tried to take the air out, but sometimes air gets caught in the dialyzer which is impossible to see. When this happens, the nurse or tech will slap the dialyzer while running the machine to get the air bubbles out. When she started the machine with my needles inserted and attached, a long string of air bubbles started to flow through to the venous line and into my bloodstream. I immediately

yelled at her and told her to stop the machine, and asked if someone else could be my nurse that day.

Once, as a transient patient, I was receiving treatment at a facility that was quite simply a horrifying place. Three separate incidents took place between two treatments that are illustrative of the potential for mild to serious medical problems. The machine alarm of a patient across from me was alarming about every minute. As stated earlier, once a machine alarm it typically stops the blood flow. As stated earlier, machine stoppages are usually caused by high venous or arterial pressures as well as by there being air in blood. The patient in this case had a vascular access that obviously was not working properly. The staff member made no attempt to fix the problem and would leave the machine alarming for *minutes* until they started the machine again. A stopped machine should be taken care of within 15 seconds or less to prevent blood clotting in the machine. Sure enough, some 45 minutes of this continuous action led to machine clotting and the patient losing her blood.

During the same treatment, I noticed two hours into my treatment that my heparin chamber was empty. Heparin is a blood thinner given to almost all patients during their treatments to prevent clotting in the machine. Typically, a bolus of heparin is given at the beginning of a treatment and then a small amount is continuously through the machine during treatment, and then usually the heparin is cut off for the last hour of treatment so the needle sites can clot when treatment ends. In the situation I was referring to, if I did not receive heparin soon the machine would have clotted and I would have lost all the blood in the machine. If I had not been aware that the heparin chamber was empty (or what heparin was in the first place – a fact of which some patients are totally unaware), I would probably have lost my blood in the machine.

While this type of incompetence at a dialysis facility is uncommon, it shows the overall lack of professionalism of this particular dialysis unit. More incompetence became apparent during the next treatment when I felt my blood pressure starting to drop two hours into a four-hour treatment. Typically, if I experienced a blood pressure drop it would happen in the last hour of treatment as I neared my dry weight. The goal the machine was set for that day was 3 kilos, but my pressure had dropped with only about 1.5 kilos taken off according to the machine. I had the staff member lower my goal to 1.8 kilos because my blood pressure had fallen pretty severely. At these moments, my brain is telling me that if I lower the fluid goal I will be over my dry weight by 1.2 kilos when I leave treatment. I would have all the extra weight on so I won't have the ability

to drink hardly anything until the next treatment. However, the body is an excellent predictor of dry weight, and many times it was important to go by how I felt instead of the stats.

When I weighed myself at the end of treatment I discovered that how my body responded was correct and that I had actually achieved my dry weight half way through my treatment. In reality, the machine was calibrated so poorly that it took off an *additional 1.2 kilos* of fluid. At most dialysis facilities, machines are checked routinely so that the over-removal or under-removal of fluid during treatment does not take place. This protects patients from either removing too much or too little fluid.

### Fluids

When I would wake up in the middle of the night while I was a dialysis patient, I would go the kitchen and grab an 8-ounce tumbler from the kitchen shelf, filling it halfway with water from the sink. Putting the rim of the cup to my lips, I would slowly tip the glass back and let a small trickle of water through to fill my mouth. My throat would contract to briefly prevent the water from pouring down to be forever gone. Each slow swallow was an extreme pleasure. It took about 30 seconds to drink that cup. Those were my favorite times of the day.

It is hard for most people who live with access to an endless supply of fresh water to appreciate the pleasure one can get from drinking. Hemodialysis patients do not have the privilege of being able to have a glass of water whenever it is needed. Since the kidneys expel wastes from the body in the form of fluid, people who do not have a working kidney or kidneys have that fluid in their system until it is removed by the machine. Since patients are typically dialyzed three times a week, the amount of fluid buildup is significant which can cause severe issues if ignored. The typical restriction for patients is 1 Liter/day, or about 32 ounces, which equals 4 cups/day. Extra fluid in the circulatory system causes edema, wet lungs, ascites and hypertension.

Strangely, immediately after treatment (when I was most dehydrated), I felt little need to drink anything. The next day I would start to drink and as the day continued the need to drink would grow. As the amount of toxins increases in the body, the body responds and stimulates the need for more to drink. So as time progresses from the last treatment, the need to drink increases. Obviously, this is an extremely difficult situation since the need to drink is a feeling that I would assume to be similar to the need for an addict to get a fix. I knew it would cost me if I took that extra drink (as other patients knew), but I would do it regardless.

For me, this was by far the most difficult aspect of being a patient. Drinking is something that most people do without thought. For dialysis patients, the act of drinking is one of many moments of the day when their disability manifests itself. Every time that I would start to contemplate having a drink, or a situation would present itself when drinking was involved (a meal, a social occasion, passing a drinking fountain), I would have to calculate how much I had to drink since my last treatment, how close I had got to my *dry weight* during my last treatment, on what other occasions I would be drinking before my next treatment, how far into the future my next treatment was, and how I felt. During the course of treatment, the extra fluid is removed through the machine with a goal of achieving a patient's "dry weight." The dry weight is the weight each individual person at which they are slightly dehydrated and any "extra" fluid has been removed. It is essentially the weight achieved just before there is a drop in blood pressure. The purpose of achieving the dry weight is to prevent the swelling, wet lungs and hypertension that is caused by carrying around excess fluid on a consistent basis.

As opposed to the long-term effects of fluid overload, there were three negative outcomes from too much fluid intake between treatments. The first was purely a matter of physical impairment. As the amount of fluid increased in my body, I would start to swell, feeling it particularly in my feet and my hands (edema). If enough fluid entered my circulatory system, it would become difficult for me to catch my breath. Tuesday mornings were the worst for me since it would be three days since the last treatment, from my being on a Tuesday, Thursday, Saturday schedule.

Between treatments, personally I would typically remove between 2.5-4 kg of fluid. The most I ever removed was 5 kg, or 11 pounds. The removal of such a large volume of body weight as 5 kg puts pressure on the heart and the body. Because the heavy weight take-off days would be exhausting, I would suffer from severe fatigue and dizziness until I woke the next morning. There was also a fairly high chance that I would become hypotensive and suffer the effects of low blood pressure.

One thing I was able to accomplish over the course of six years was to manage my fluid intake. One of the major issues I had during my first period of being on hemodialysis from 1998 – 2000 (between 20 and 22 years of age) was the lack of any type of system to limit fluids. While at college my fluid gains were not bad, my return to my mother's house (and the subsequent boredom of a life of work and nothing else to do) led me to spend my time at home with nothing to do but

think about eating and drinking. I remember distinct moments where I would be sitting on the couch watching television and thinking about the bathroom sink, pondering whether to go and turn the water on to a trickle and slurp at the water as a dog might from its bowl. It was as though there were some madness that overtaken me, and all I could think about was that which I could not have. At times I would wake in the middle of the night and contemplate the bathroom sink and the cool water that was waiting to be drunk. It was a constant fight between the natural tendency to want to drink and be satisfied on the one hand, and the significant discomfort before, during and after treatment on the other hand. Add that to strange, pathological thinking and obsession-laced thoughts, as one might call these obsessive drives an addiction. For those first few years when the natural tendency to drink was stronger, I suffered because of it.

During that short stretch of time between my completing college and my first transplant (June 1999 – February 2000), I had the most difficult time controlling fluids. Between each treatment I was gaining at the least four kilos and many times over five kilos. Because I was unable to get to my dry weight after treatment, fluid continued to build and build in my system. Walking around became painful since my ankles were constantly swollen from too much excess fluid in my system. At times I would have trouble breathing.

There were a couple of reasons for my state. One reason for my fluid problems was that I was generally inactive. Being bored with nothing to do at home, I had too much time on my hands to obsess about drinking, making my thirst worse. Secondly, I was lying to the nurses and techs at the dialysis unit about both my fluid gains and my dry weight. The staff were not vigilant at the dialysis unit in Buffalo about watching patients being weighed, so the weights I reported were determined by how much I could bear taking off, not how much needed to be taken off. I fell into a cycle of gaining more weight than I was taking off and by the time I had my transplant I weighed close to 190 pounds. One month after the transplant I weighed 147 pounds.

Cramping is yet another issue that hemodialysis patients have to deal with during treatments as part of fluid control, affecting 33% - 86% of patients. Due to the fluid changes in the body during the course of treatment, patients feel the effects of cramping usually in the last hour, sometimes severely so. For me, would get the worst cramps in my back, abdomen and hamstrings, which were extremely painful. Sometimes I would get a cramp in my jaw after yawning and the pain would be excruciating in such a sensitive place.

After getting a cramp, there was not much relief from the pain. Any attempt to minimize the effects of the cramps would be offset by something else. For instance, a bad leg cramp could be worked out slightly by either sitting up in the chair or pressing the effected leg on the ground with the foot. Why this method of relieving cramps is problematic is that during treatment patients are required to sit in recliners in the prone position. Sitting back is essential to keeping blood pressures from dropping. The more towards upright is the patient, the lower the patient's blood pressure will be. So letting patients sit up and press their feet against the floor to relieve a leg cramp is dangerous because more than likely they will experience a drop in blood pressure, further complicating the situation. Other attempts to deal with cramps are stopping the fluid withdrawal and giving IV saline to patients. Most dialysis facilities have packages of dried chicken broth to which one adds hot water. This is used in the case of cramping and hypotension, but adds both fluid and salt to the imbiber.

The third result of too much fluid intake was, surprisingly, the lecturing and nagging from the staff about how much fluid other patients and I would gain between treatments. Sometimes the staff would say things like "whoa," or "have a good time this weekend?" I was never personally lectured, but I remember one incident where the nurse manager piled six 1kg bags of saline on a patients lap and said, "This is how much you drank in the past two days!" Of course, this sort of thing generally made patients resentful since the staff members had no idea how difficult it was to limit the amount you drink, especially when the body is telling one to drink.

Patients (including myself), would play cat and mouse games with the staff about fluid gains. Before being put on the machine, every patient had to be weighed to determine how much fluid was gained between treatments and how much weight needed to be taken off to reach their dry weight. If I gained too much fluid between treatments, I might lie about my actual weight so I would not have to deal with questions and criticisms about how much weight I had gained. Also, the staff wanted to make sure that patients always got to their dry weights by the end of treatment, and I would want to avoid the discomfort of taking off 5 kilos of fluid. Instead of reporting a gain of 4.5 kgs, I might say that you gained 4 kgs. The extra half of a kilo not taken off during a treatment could make the difference between feeling really drained after treatment or merely tired.

## People

From the array of mishaps and problems already discussed (and perhaps from popular representations or common knowledge assumptions about dialysis), people have a general impression of hemodialysis as being a painful, traumatizing experience, full of danger and uncertainty. The reality is that hemodialysis, despite rare and brief moments of fear (and sometimes absolute terror) is simply boring and occurs overwhelmingly without incident. Most patients sleep and watch television. I usually read a book or talked to staff. It was simply a way of dealing with the endless hours of drudgery that treatment becomes.

Understanding how the opportunity for a relationship to develop is illustrated by how a typical dialysis day proceeds. The nurse or tech informs a patient that the patient's chair is ready. The patient is then weighed; blood pressure and body temperature are taken, followed by questions concerning the patient's general well-being. Needles are inserted, tubes from the needles are hooked to the tubes from the machine, the machine starts and treatment begins. During the course of this procedure the caregiver is constantly taking readings from the machine and recording information to a patient's "flow chart" (the flow chart is a record of various measures of patient status of the entire treatment). The time it takes for a staff member to call a patient into the facility until the machine is up and running is about 15-20 minutes. Every half hour a caregiver takes more readings from the machine. Likewise, removing a patient from the machine is takes 15-20 minutes.

The result of this structure is that relatively close relationships have the opportunity to develop between patients and staff (mostly determined by the openness to a relationship by the patient). Many patients sit through these treatments treating staff members on a strictly professional basis and seem generally disinterested in the staff member's lives. These patients are solely concerned with getting through their treatment, seeing the staff members as simply serving their own needs.

On the other hand, many patients like myself pursue interaction out of friendliness and boredom. Staff members have a modest amount of down time between patient shifts, and most are willing to talk. From personal experience, people who work in dialysis (the nurses and techs) tend to be outgoing – perhaps a result of constantly working with people or a selection effect. My personal take on these workers is that they are a little "crazy." There is a certain degree of madness and stress involved in the job, and the position requires a degree of courage and toughness that most careers do not entail. It's safe to assume that the "survivors" have the constitution (and



personality) to deal with these stresses. Interaction with friendly patients is a way to deal with the stress and the boredom.

The administrators of hemodialysis units (and the charge nurses as well) are wary of these relationships. Although the patients themselves are never forbidden to interact with the staff, I have both witnessed and been told of the line that the administrators try to create dividing the staff and patients. The separation would have multiple functions: keeping the staff away from wasting time talking; preventing staff from playing favorites; and letting information slip about the dialysis unit and its administrators that might put them in an unfavorable light.

As most modern organizations or institutions function, dialysis units rationalize the work process and control information. Many dialysis units are for profit, the two biggest being DaVita and Fresenius, both publicly traded companies. Some dialysis units are non-profits and some which are state run. In my experience all dialysis units are pretty much similar, and differences rely on the individual administrators' capabilities. What all dialysis units do have in common is that the company controls information to a great extent, with patients being told little about the inner-workings of the organization.

Close relationships between the staff and patients complicate the social distance artificially created by the administrators. As caregivers, nurses and techs have a natural tendency to be concerned about the health and well-being of their patients – especially for patients they like. This can be an awkward situation for the caregiver because they are also required to perform the role that the organization demands, roles that at some times are in conflict.

A nurse at a former dialysis facility once told me about the process known as dialyzer reuse. Dialyzers (or artificial kidneys) are products that contain membranes that absorb toxins from the blood during treatment. In the past, many patients reacted poorly to brand new dialyzers (called “first use” syndrome), and facilities began cleansing each individual's dialyzer and reusing that dialyzer for each treatment. The practice had the added benefit of reducing costs because dialyzers are quite expensive - \$30 to \$150 per unit (Baxter 2012). Reuse, if conducted with proper care (according to American Medical Association guidelines), is cost effective and safe. At the time I was reusing a dialyzer. I was told by a company official (either the nurse manager or the administrator), what reuse was and the advantages of it. This nurse, on the other hand, was suggesting that the process was not at all safe, and he was seeming to suggest that I stop reusing

my kidney. It is hard to say whether he offered this information to other patients – the nurse and I had a good friendship.

Interactions between patients and physicians are dependent on the dialysis facility. In some cases, patients will visit nephrologists and general practitioners in the doctor's own offices. Some of the facilities would have the doctors give consultations with patients during treatment. The doctors (and usually their fellows), would go to each patient usually once or twice a week and see how things were going. These interactions would last about one to two minutes, usually ending with the physician asking if the patient needed any prescriptions.

Personally, particularly when the doctors would review with me my monthly blood work numbers, I became nervous and defensive. The doctor, depending on personality, would be either supportive or suggestive when my phosphorous was too high, while others could become lecturing. First off, I was always nervous about receiving my numbers. I had struggled with high phosphorous during my years on dialysis, and having high phosphorous over a long period leads to serious health problems. It was not only the fear of having continuously high numbers that was the sole source of that nervousness but also the embarrassment of the impression that I was not able to control myself. The numbers, according to the doctors, do not lie and it was difficult to manage the contradiction of “appearing” as a compliant patient and the actual reality that was printed on a piece of paper. There was also a degree of resentment involved. Who were these people to lecture me on controlling my diet? The way I saw it was that they had no right to make judgments about my eating and drinking habits when they themselves had never had to deal with the limitations that we had as patients.

Dealing with people who were not patients, particularly people who know one's condition and one's special diet, can be an extreme chore with which to deal. Personally, I thought day and night about drinking and eating, what I could have and could not have, bordering at all times on the obsessive. From some people (especially those within your immediate family), there would be constant questions and “suggestions” about what you should or should not eat. It is hard to describe the anger I would feel in those situations. For all the obsessing and worrying about drinking and eating, and all the sacrifices being made day and night of small pleasures that most people never think twice about, someone would try to control me and tell me what I should be doing. You could yell at family members in fits of rage, but you had to hold your tongue with the doctor.

## **“Bad” Patients**

These close relationships I had with some of the staff members became a source of tension between myself and Daniel - another patient. He was male, about 60 years of age with a strong, Long Island working class accent. He was generally defiant with the staff, getting into verbal spats often. Daniel brought beer and cigarettes into the treatment facility a few times – mostly (I would assume) to taunt or instigate the staff. He intimidated most or all of the female nurses, while the few men who worked at my facility thought he was “crazy.” As I was leaving treatment one night, walking past his chair, Daniel muttered “brownoser.” I asked him why he called me that, and he said that I was overly friendly with the staff so that I could get preferential treatment. I told him that what he said was rude and insulting, and that he knew nothing about me or my motives. That appeared to silence him.

Daniel’s perspective (and behaviors), represent a particular attitude toward the facility – that these people are there to punish him. From what I gathered (he refused to be interviewed), he distrusted the entire enterprise of dialysis. He formed no relationships that I know of with the staff. The only person who worked at the dialysis unit who spoke with him on a consistent basis was Jean – a Haitian immigrant and former soldier who thought Daniel was “crazy.” Jean actually tried to explain to Daniel that I was not getting special treatment from the staff, but that it was simply that my treatment started earlier and thus I left before most of the patients on the third shift left. A few months after the incident between him and me he apologized, and we shook hands. The last I saw of Daniel was when I returned to the dialysis facility to recruit respondents for my dissertation research. He did not recognize me – a nurse told me that he “didn’t really have it there anymore.”

Antagonistic relationships between patients and staff members were rare. During more than six years of receiving treatments, the number of outbursts of anger in interactions between patients and staff was less than ten. However, all of those situations involved a middle-aged, male patient. There were also moments of disorderliness and resistance from some patients. Most of them either died during the time I was undergoing treatment or were showing signs of decline.

One particular episode involved a middle-aged man named Pete, a former musician. I saw him one day being wheel chaired into the room, looking terrible. His eyes were sunken low, with bags under them as big as suitcases. He stared blankly ahead, surely stoned off his rocker. Pete took whatever was available (or what the doctors provided – and sometimes what they could not); that day it was probably methadone, percocet or valium. He fought one day with a doctor over renewal

of a pain medication prescription. Pete and I usually exchanged greetings during our treatments – that day I am not sure he knew who I was. Later the next week he told me that he had an incident – he had gone “insane” and pulled his needles out during his treatment. He seemed strangely calm in his retelling of the story. But that day he was a zombie, pumped up with so much fluid and drugs that I could not believe that he was still alive. All of his shoelaces were undone to their loosest settings to allow room for his tremendously bloated feet. I am glad he sat in a chair that was out of my line of sight so that I did not have to watch. During the next few weeks I rarely saw him at treatments, most of his time was spent in the hospital. A few months passed before I saw him again at dialysis. I had assumed that he had died weeks before since I had not seen him, but he was there and looking absolutely horrible. I was astounded that he was still alive. He died shortly afterwards.

Another patient, Charlie, a thin, pale man in his fifties was constantly on his cell phone during treatment talking loudly, mostly about business. I even remember conversations he had that involved looking for a donor kidney. A rumor was circulated around the dialysis unit that Charlie was paying someone for the kidney, something that is generally looked down upon by people in the transplantation business in the United States. Once, when he got into an extremely heated exchange with one of the nephrologists when the doctor refused to refill his prescription pain medication, Charlie threatened to sue the physician.

Charlie and I talked sometimes and exchanged greetings usually; I found him to be a friendly person. There was a time when he relayed a story to me that he had found someone to donate a kidney to him. However, because of his general poor health (and I suspect his drug use to an extent) the surgeons cancelled his surgery and postponed it until he was able to get healthier. Charlie never got healthier, and died without ever having his transplant.

Albert, a tall heavyset man in his mid-fifties, was constantly having trouble controlling his fluid gains. As with most other men and women at the facility who were sociable, Albert and I exchanged greetings and sometimes spoke briefly. Once, a staff member told me that Albert refused to stop chewing his gum during treatment (chewing gum while undergoing treatment was restricted by the management), so the nurse manager informed him that if he did not stop chewing his gum he would be taken off the machine. Albert refused and he was sent home.

As already mentioned, Albert had a lot of trouble dealing with his fluid intake. He was consistently taking off 5-6 kilos per treatment in fluid. The repeated high fluctuations in body fluid levels and the resulting adema was taking its toll on him. During a conversation, Albert excitedly

told me that he had started taking fen-phen (or Fenfluramine/phentermine), the once popular and now FDA-barred diet drug. I never asked how Albert got access to the drug (this was 2007 while the drug had been taken off the market in 1996), but he said that on the drug he did not feel thirsty all the time. Albert said that he had also lost about 30 pounds since he had started taking the drug about a month before. Albert died shortly after our conversation. I never found out why.

## **Discussion**

Obviously, these examples of “bad patients” in no way follow from any systematic mortality rates measured in studies. They are simply my most vibrant memories of patients who had trouble dealing with the rigors of treatment. What is useful theoretically is to think of these as those “outlier” cases, patients so woefully bereft of any notion of how to stay healthy and deal with dialysis, or being so antagonistic with the orders of the staff and physicians that they do the opposite. What is common to all of these cases is that these are middle-aged men. It is entirely possible that this is purely coincidental, although it fits some of the data from the previous research that shows patients in their middle age are the most depressed and the least adherent. However, the lack of robust statistical results on the gender variable both in the quantitative analysis and the literature raises an important counter-point.

A substantial literature exists that takes up the problem of gender and health that may provide some thoughts on how to approach this issue. One key perspective looks at the relationship between gender, social class, and dealing with chronic illness. Among all persons with health problems, men are much less likely to seek a physician than women, poor men specifically so (Wilkins 1998). These gender and health differences have been explained through the theory social construction, that argue that men’s overemphasized attempts at performing masculinity hurt them physically. From a constructionist’s viewpoint, being a man is something a man *does*, not *is* (Courtenay 2000). Gender, in short, is performative rather than essential to one’s nature. Since most modern conceptualizations of masculinity are based on power, men perform masculinity by being autonomous and individualistic. Being a man is associated also with social status. With these conceptualizations from the social constructionists in mind, it makes a fair amount of sense that working class men have the most to “prove” how manly they are. By being positioned lower on

the status scale than their middle- and upper-class male counterparts, they compensate by being overly independent and sure of themselves when it comes to their illnesses, and in many cases defiant to those who try to control them (wives, doctors, nurses, etc.). The resulting “deviance” in the case of hemodialysis, in my observation, was actually deadly.

Likewise from my observations, those of more “moderate” temperament made better patients. I would certainly put myself in that category, as well as some others I have yet to mention. The opposite to the men described above are patients like Jimmy. Born with juvenile diabetes, Jimmy had lost his kidney function as a result of that disease, as well as suffering damage to his heart, pancreas, and other organs. Jimmy was in his early 50’s - tall, lean, and full of vigor and energy unlike most patients. He was relentlessly compliant, easily accomplished from living from his birth with a limited lifestyle. Another patient, Samuel, a man in his late 60’s with whom I shared treatment times, always had his laptop with him. He was always well-groomed and alert during treatments, working on his laptop (he is a stockbroker). Both men dealt with treatment and their regimens with ease, always having positive interactions with the staff. Although treatment itself is only a part of the experience of being a hemodialysis patient, these treatments are extremely important for overall adherence. While most of the emphasis is placed on behavior outside of the dialysis unit by caregivers (diet, taking medications, fluid gain), receiving a full, safe treatment is supremely important for patient well-being, and to my knowledge self-awareness during treatment is emphasized to patients. While watching phosphorous, potassium and fluids outside of the dialysis unit is important, it is the machine that does the work of removing wastes and toxins from a patient’s system. Each time some difficulty arises during treatment (a patient’s blood is left in the machine, a treatment is cut short due to hypotension, or a vascular access is damaged), it increases the chance that these patients will be adversely affected.

While the quantitative analysis in chapter 3 provides an answer to how having a well-educated family leads to better adherence, it does not provide evidence of how higher family education leads to lower fatal incidences during treatment because the patients with these backgrounds are more vigilant during treatment (citation which shows link between SES and treatment death). Having personally experienced hemodialysis treatments, it is safe to assume that it is in the patient’s own power to make sure that they have a successful treatment. While I know of no study looking at how patient behavior during treatment leads to better or worse adherence rates, it is simply hard to argue that these incidents are completely random. Therefore being active,

engaged, awake, aware, disciplined and most of all knowledgeable of how the dialysis machine works are very important for avoiding incidents that lead to overall non-adherence and fatal events.

## Chapter 7: Problematizing Adherence

This chapter is an attempt not only to both theorize and problematize the notion of adherence, but also to place it within an historical context. What lies at the heart of this discussion is the historical processes of what I call “normalizing” that have taken place in western civilizations during the past 200-250 years. With the ascendance of modern scientific discourse, as well as the growth of modern institutions as symbolic of the modern state, individuals have in many ways become products of these historic forces. From birth to grave for the majority of people in western societies, individuals are monitored, surveyed, calculated, and measured. For modern government, it is necessary to develop, socialize, and discipline individuals according to a standard of normalcy that makes modern life possible. This fact, I argue, has implications for what we consider “healthy.”

What follows in this chapter is an introduction to Foucault’s ideas about the development of modern institutions and the resulting consequences for our definitions of health. That discussion is expanded by Goffman’s ideas about normalcy as the ability to appear, or play the role of, the healthy person. Finally, I offer some conclusions about what these ideas mean for Parsons’ original conception of the sick role, as well as some larger implications for medical sociology in general. The essay here is not an attempt to “explain” some of the findings from the previous chapter, but to perhaps let us think about and re-conceptualize what it means to be healthy.

### **Adherence as a Historically Developed Conception**

Adherence itself cannot be fully understood without first placing its existence within a construct of a western-based model of medicine. The intent here is to be critical of that model – not from a normative perspective which attacks the western model as something “bad”, or a model that is generally negative – but rather to see how medical knowledge is based on a discourse of healing that has existed in the Western world for some centuries. I argue that this particular discourse of knowledge about “health” or “medicine” or “care”, is completely circumscribed by the development of larger discourses of knowledge. Patient adherence is not simply a practical



solution to being healthy, but rather is a symbol of the dynamics of behavior in the modern, Western world where institutions – whether educational, occupational, or health centered – play a central role.

These larger discourses of knowledge are the object of Michel Foucault's archeological analyses of western institutions, notably his treatments of asylums and prisons. It is not my intent here to argue that dialysis units are comparable to asylums or prisons, but rather to assert that thinking in terms of "adherence" is part of a much larger system of knowledge and power that drives all contemporary notions of health. The major features of power that are brought to bear on those that are "ill" (a grand assortment of people) are the confession, judgment, and surveillance. These concepts will be discussed later in the chapter

This archeological history relates to the larger development of what Foucault might call traditional western institutions. He sees the confinement of the insane (and the other groups mentioned) as the beginning of a trend in the West in terms of how deviant populations are handled, lasting until the present time. More importantly the history of the institution, not coincidentally, follows quite closely the move toward rationalization of the economy and the development of the modern nation state. Put simply, the containment of problem populations is an economic issue, and the treatment of such populations is informed by the rationalistic enterprise in general.

The confinement of those "problem" populations during the 17<sup>th</sup> century – criminals, prostitutes, beggars and the insane – was at first an all-encompassing affair (Foucault 1988). After the Enlightenment, a scientific discourse developed that created a sophisticated classificatory system of deviance. Many scientists had come to realize that mental illness was itself an altogether different entity than common criminality, and the treatment for such required more than simply imprisonment – hence the rise of the modern psychiatric hospital beginning in the late 1700's and early 1800's. Moreover, the confinement of the pauper was soon realized to be misguided as poverty came to be recognized by governments as normal features of modern economies rather than a sin or solely a personal responsibility. The poor were shaped and made into useful economic pieces. However, despite advances in both science and a more liberal and humanitarian view of the insane, the institution remained a place of confinement for them.

The history of madness Foucault relates is only a piece of a larger project he has in mind – the analysis of western institutions and the systems of power they entail. The mental institution, or mental or psychiatric hospitals that appear in the early 19<sup>th</sup> century are the substantiation of that

power. Also, alongside the appearance of psychiatric hospitals is the creation of quite similar apparatuses in form and function – the modern prison, the military barracks, the hospital and the school. Foucault aggregates all of these phenomenon into one category – physical spaces whose intent was to create a mechanism whereby people are either developed or controlled at a mass scale to make modern societies function.

At the center of the transition that takes place between the classical and the modern age in terms of the treatment of the insane is one of practicality. Foucault is uncomfortable in claiming that emerging “treatment” of the mentally ill was humanitarian in focus, but rather he argues that it represented a new way of dealing with this population based on the emerging political order after the French Revolution. As a result of the publishing of the Declaration of the Rights of Man, no one could be imprisoned who had not committed a crime. Therefore, most deviants and political prisoners had to be released, and something had to be done about the insane. Those who were left to be confined were criminals, the topic of Foucault’s *Discipline and Punish* (1977) to which we will return shortly.

Since the insane could no longer be confined indefinitely without reason, the mental institution or mental hospital was created. Although there was a medical discourse developing concerning insanity, it had not quite reached the power and breadth that modern psychiatry has today in terms of the treatment of mental illness. The founders of these hospitals were religious reformers, not doctors, the most famous being Tuke and Pinel.

The method employed was no longer to simply exclude and silence, but to “normalize” madness. Patients at psychiatric institutions were encouraged to talk and participate in the “normal” everyday activities that for the general population seemed to accomplish effortlessly. Foucault relates the activity of the tea party, that archetype of bourgeois culture, as the opportunity by which the patients would learn the habits and inner sense of control that dominates middle class life. Patients were “taught” the ways of polite society as an attempt to reform them.

As contrasted to forced and physical oppression, Foucault asserts that there now existed mental oppression. While the chains and dungeons were now gone in place of freedom of open yards, the cost of that freedom was constant surveillance not only externally from the operators of the asylum, but also from the “moral” surveillance taking place by physicians and reformers. The asylum keepers created a situation in which patients are forced to view their situation from a rational and

moral basis, and to understand their condition as being possible to alter. In a sense there was an inner surveillance now present (the all-seeing eyes of God) as well as the outer surveillance of the staff. Both types of surveillance were in a way managed by the authoritarian figure - at first the religious reformers like Tuke and Pinel, and then the medicalized form under the psychiatrists. While no longer “beasts” as they were treated before the 19<sup>th</sup> century, they became human subjects capable of becoming disciplined with the oversight of those with knowledge and power.

Corresponding to the transition from confinement to rehabilitation is a transition in those with control over the discourse of “madness” – that is from political bureaucrats originally interested in the insane from a perspective of social control to the establishment of the mental asylum armed with a medical-legal discourse proliferated in books and medical journals. The “truth” of madness had changed, and those that created that “truth” had established themselves as the “power” in this field as sanctioned by their increased legitimacy through the developments in the human, social, judicial and medical sciences. The peak of this legitimacy began in the first half of the 19<sup>th</sup> century and continued until the anti-psychiatry movement in the 1960’s.

While Foucault notes this situation, or treatment, is much more humane than the previous era of confinement, he does not see it as humane as such. Rather, the inner control being diffused throughout a previously “undisciplined” population as more insidious in many respects, a new system of power that is establishing itself as the center of modern life. Similar approaches to issues of social order and control develop alongside the increased legitimacy of the sciences in general, leading to what Foucault calls “the establishment of man as a subject,” explored significantly in *The Order of Things* (2002).

Inherent in this view is a rather obsessive need for classification and ordering. Madness becomes separated from criminality, which is of course separated from poverty and sexual licentiousness. Within these larger categories of deviance are further subcategories of explanation, resulting in a hierarchically classified system of knowledges. This classification corresponds to the development of “disciplines” as we know them – sociology, medicine, psychiatry, economics, criminology, and so forth. And with the development of disciplines is the development of discourses – legitimized texts that account for the current state of knowledge in each field, rigorously homogenized so that a system of truth can be established. Minor, or alternative discourses, are delegitimized and relegated to dustbins. While a traditionalist might see this

development as the proper development of science as such, Foucault sees this historical process as somewhat insidious, where a system of power over the “truth” develops in favor of other truths.

Man “as subject” defines humans in terms of a classificatory scheme in a taxonomy as an animal might be – recorded in form as minutely as possible, including biological, sociological, economic, historic, criminal, medical, and the like. With these developments (and certainly reinforced by revolutionary advances in industrial production) comes a view of humans as mechanistic creatures, understood as part and parcel of the machinery of society. Man becomes part of the architecture of the world, able to be shaped to fit its purposes.

Modern institutions (the school, the barracks, the prison, the asylum, the hospital, the modern corporation) all function and depend upon these knowledge systems and could not continue to operate without organized, disciplined and docile individuals freed from the constraints of nature and heterogeneity. Institutions both *depend upon and create* these bodies<sup>14</sup> – the school to instill initial discipline, the corporation to be efficient and productive for the greater economic good, and modern medicine and its apparatuses to normalize patterns of good health.

The mechanism by which modern institutions “create” individuals from some undifferentiated mass is of interest to us for several reasons and begs these questions to be answered. First, what is the process by which a person is “normalized” or controlled by the institution. Second, what are the consequences of such normalizing processes – what happens when they succeed and what happens when they fail? Third, of what benefit is this process of normalization which still affects our lives today? Last, does the consequence of that normalization have implications for health and illness?

### **Adherence as Performance**

Aggregating the above-mentioned diverse group of institutions was not a revolutionary thought – Goffman had done so a decade before Foucault in *Asylums*, most notably his essay, On

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<sup>14</sup> Foucault uses the term *bodies* as opposed to individuals. This implies the impression that the body is utilitarian and subject to control and inscribed with disciplinary power. The word *individual* implies agency.

the Characteristics of Total Institutions (1968). Total institutions, according to Goffman, are places where all aspects of life are controlled by a central administration with an overall rational plan. Examples of such institutions are prisons, mental asylums, boarding schools, army barracks, tuberculosis sanatoria, monasteries and many others. Goffman finds these places interesting and powerful because an attempt is made by the organization to manipulate and change the self.

Starting from the assumption that identity is salient to the milieu of persons (drawing from Mead's work (1967) on the self, total institutions find these milieus detrimental to stabilized social control. For instance, the drug user's sense of identity draws from his or her stable set of social arrangements in their immediate environment. The institution views those social arrangements as the source of dysfunction and deviance since these relationships reinforce an unproductive identity, so elimination of those networks and the subsequent effect on identity is key. Cutting away of these sources of identity is an aspect of mortification of the self, a process in which identity is in essence "killed" in favor of whatever form the institution intends to create from this person. In some cases the prison wants to create inmates that are intense rule followers, yet in others the army wants to make them disciplined killers.

A central aspect of mortification of the self is the psychological game that is played by the staff to humiliate the patient/inmate into exposing the truth. The "mask" that Goffman finds so necessary for identity in modern life (and discussed in great length in *The Presentation of Self in Everyday Life* (1959)) must be removed to manipulate the subjects' inner nature. In looping, for example, subjects attempting to save face by using sarcasm and derision are punished further for their insolence. Actually, the face saving (a normal tactical response in everyday life) is disallowed, as it is seen as a symptom of disease and abnormality as it is tied to a "bad" identity. While in public life a drug addict may engage in a series of behaviors that mitigate the imposition of a negative identity, the drug addict in a rehabilitation center has no recourse but to accept their spoiled character. The excessive surveillance and complete lack of privacy are essential to all total institutions to accomplish the "fixing" and rehabilitation of their subjects.

In Goffman's view, rehabilitation in the total institution is equated with normalizing. Curing the mentally ill is essentially coercing the patients into internalizing the worldview of the staff. Surveillance plays a crucial role in rehabilitation (as it does in Foucault's eyes). Also, similar to Foucault, the "soul" is disciplined and punished so that the surface presentation now reflects the

inner self. The perfection of the outer shell reflects the inner perfection of the soul. The acceptance of the demons inside and the expulsion of those demons through guilt and judgment is the path to normalization and good living.

It is perhaps not coincidental that both Goffman and Foucault's first serious academic enterprises – their dissertations – focus on the relationship between the purposes and functions of institutions on the one hand, and mental illness on the other. Both authors use the dynamics of the mental asylum as the jumping off point for larger more general projects. For Foucault he first makes a lateral move and discusses prisons in *Discipline and Punish*, but then expands outward with knowledge systems in *The Order of Things*, and human sexuality in *The History of Sexuality* (1978). Goffman, similarly takes a more general, more encompassing perspective with *The Presentation of Self in Everyday Life* (1959) and *Stigma* (1963), culminating in the theoretical *Frame Analysis* (1974).

Both Foucault and Goffman see that the mental asylum and generally the way in which Western societies treat and deal with their mentally ill populations, as the clearest and most stark representation of how the entire population is managed. Even within Goffman's discussion of total institutions, he hints at a more universalistic argument in that many of the features of the total institution exist in modern life - perhaps most importantly mortification of the self and the apparatuses that exist in everyday life enabling that mortification. While in the total institutions the intent is to completely mortify, one could say that there are moments in everyday life where surveillance and discipline take on similar functions. The most obvious occurs in family life between parent and child, although it is difficult not to see that the classroom has a similar dynamic. These social settings are instances where face-saving is typically punished, whether it is for "sass" or "talking back" at home, or using previous negative information of a student to embarrass them. They never rise to the level of looping (criticizing the act itself of face-saving as a symptom of denial of the disease or sickness), but the disciplining exists along the same continuum as a process of normalization and control.

Goffman was never clear about the political and economic implications of his theories of impression management, nor was there any attempt by him to situate these activities historically. Parsonian functionalists might claim Goffman as essentially describing the maintenance of the social system. Modern organizations cannot function properly without members of the

organization committed to continuously reinforcing the legitimacy of these institutions by presenting “fronts.”

Marxists could claim that Goffman is essentially describing the “front stage” of capitalist production. The maskings that Goffman describes in creating a front stage are necessary for capitalistic commerce to exist. According to Marx (1867), commodification is used to describe the process by which something that does not have an economic value is assigned a value and hence how market values later replace other social values. Organizations or businesses in capitalist production rely on workers to present the company in the best possible light, transforming a traditional fee for service relationship into a commodified relationship, where the worker is transformed to extract the greatest amount of profit possible from a consumer. While Marx’s own work focuses simply on the commodification of wage labor (particularly in factory work), it is not a stretch to see how alienating low-paying service sector work is (in this case retail) contributes to capital accumulation. However, whether Marxists or functionalist, the socialized, disciplined, and controlled individuals are foundational for modern life.

The key is in how all of the practices formed by these arrangements, either institutional (prisons, schools, mental asylums) or semi-institutional (the family), are guided by processes of surveillance, judgment, discipline and control. It should not be surprising that contemporary notions of health are determined by these same mechanisms. “Adherence” is the overarching theme in health in Western societies when it comes to health, whether it is adherence to a healthy diet, refraining from smoking, drinking in moderation, taking prescribed medication, and being open, truthful and forthright about medical issues one is confronting. One might see “health” as institutionally produced in Western societies – objectively created by the proper functioning of the apparatuses of control. One might see poor health as either the resistance to these structures, or perhaps even their failure.

### **Discipline, Adherence, and Social Class**

One main criticism that can be leveled at our contemporary methods of understanding patterns of health and illness is the complete lack of historical perspective. Epidemiologists and medical

sociologists look for “variables” that “explain” why people are healthy or not. When we find that socioeconomic status is a main predictor of health, what does this mean? In the quantitative section of this present research, I find that father’s education predicts patient adherence. We know that patient adherence is directly related to mortality rates, so we know what family education is very important for people to survive hemodialysis. This begs the question. What is it about education, or father’s education (or most likely parents education), that makes one a good patient and healthy individual? Is it simply a set of skills that are passed on to children, or does it reflect larger, normalizing social-structural forces at play?

When conducting abstract empirical analysis, it becomes very difficult to see these larger forces at work. For instance, adherence to a medical regime at first appears as logical, rational behavior aimed at the attainment of good health. Why would anyone want to be non-adherent or non-compliant? In truth, almost all patients are non-adherent (of course some more than others). What underlies the notion of adherence (the dependent variable in the statistical analysis presented earlier) is a complex socio-historical development in history, defined by Western traditions of science and social control. I find little difference between the notion of adherence to a medicinal regime (and the institutional dynamics between the patients and the staff), and proper behavior of the school child. The child that learns and has been shaped by family to properly accept the role of student (studying, working hard, and sitting quietly) is praised and made part of, and in many cases becomes a controller of, the institutional apparatus.

One could make the argument that adherence exists at the center of modern, bureaucratic life, providing an arrangement defining the law, education, health, sexuality and relationships, and the economy. The ability to navigate all of these realms of modern life is to understand and accept multiple notions of adherence, skillfully negotiating social control mechanisms by understanding these social control mechanisms and, at least, “giving them what they want.”

The brilliance in Goffman’s analysis is that he describes how a person is adherent in many realms of life, and all of it relies upon the ability to create an impression of an identity one wishes to claim. What he ignores is how one’s background determines a person’s ability to play the game of impression management. Bourdieu’s unique contribution to sociology is providing the social class context of how one successfully “plays the game” of modern, bureaucratic life (1984). While Goffman provides the framework of how modern institutional “games” operate, Bourdieu



problematizes the game by arguing, based on his notion of how social class works, that the game is stacked automatically in one side's favor. Being adherent is a middle class game, and is stacked in educated people's favor. An openness, willingness, and ability to engage in adherence behavior exists in the educated persons described in this study, while lack of discipline, distrust, and the inability to "play by the rules" exists among those patients with lower education.

Lastly, it might be useful to reflect back upon Talcott Parsons' original definition of illness in the *Social System* (1991), and the sick role that is central to that definition. Simply put, from Parsons' perspective, a sick person is a person who cannot fulfill their role obligations. He goes on to argue that those who are ill are exempt from fulfilling their role expectations until such time that they are able to be well enough to fulfill them yet again. During the meantime, the individual is expected to seek a physician's help and to strive to get better. Why this role exists in social systems is because it is necessary for the general functioning of that system. Not allowing people the time to get better would create mass dysfunction.

One could criticize Parsons by stating that, in reality, playing the sick role is a difficult thing to accomplish. Understanding what makes a person healthy in modern life is an almost impossible task, even for people with all the advantages. In fact, adherence to the sick role is, as I have argued here, a historically derived reality based on a host of institutional effects. What becomes even more complicated in modern life is the eroding of the medical discourse as a monolithic edifice, and the consumer market now begins to define those behaviors and the bodies that are considered "healthy."

Foucault provides us with a historical model of how systems of control developed since the Renaissance Period in Western societies. These systems of control and power were embodied in modern institutions – the school, the hospital, the army barracks, the asylum, and the prison. The defining feature of these organizations is the controlling of both the inner soul (to use Foucault's language) and outer appearance of the individual, by using modern techniques of surveillance and discipline, and instilling complex feelings of guilt (and hence inner control) among populations. Proper functioning of a modern, bureaucratic economy focused on capital accumulation requires a population equipped with such discipline. Adherence and health are essential to, and an aspect of, this arrangement. How we define health in Western societies is determined by the extent to which how one functions in and contributes to these rational, bureaucratic organizations.

Why dialysis adherence is so important to this discussion is that this is one circumstance of in modern life where the physical resources of social class, namely wealth, play only a partial role in enabling patients to adhere and behave. In most cases where sociologists try to measure outcomes (educational attainment, health, income, etc.), there exist myriad entangling variables that muddy the waters of what the driving feature of diverging outcomes are. All hemodialysis patients, on the other hand, regardless of socioeconomic status, are forced to submit to the same restrictions and rules, and there aren't any possible objectified resources that can substantially affect adherence outcomes. The resources brought to bear in this case that make any meaningful impact on the ability to adhere to the regimen are embodied, and are therefore tied to the mechanisms that are the subject of this paper.

It might be useful to start thinking about "success" in modern, technocratic life by engaging seriously with the notion that discipline and social control (and the techniques of surveillance) begin in early family life and spread outward. Regimentation and discipline for those with higher SES corresponds, often quite predictably, to the bourgeois control mechanisms that one encounters throughout the life course. Adherence to a medicinal regime, specifically one that requires rigid discipline and control, reflects not simply the knowledge of what one needs to accomplish, but rather, and perhaps most importantly regarding health outcomes, the "embodied" discipline with which to follow through.

## Chapter 8: Conclusion

The goal of this research project was to determine the factors that influence hemodialysis patient adherence as part of assessing the influence of socioeconomic status (SES) on health outcomes. The main theoretical paradigms for understanding the sociological factors that influence patient adherence were resource-based theories such as fundamental cause theory, Bourdieu's theory of cultural reproduction focusing on cultural and social capital, and Shim's cultural health capital theory. According to these theories, individuals accumulate or fail to accumulate skills, knowledge, prestige, and other resources throughout their lives that theoretically impact their health. A series of OLS multiple regression analyses (N=82) were conducted to measure the impact of these resource variables.

While most measures of SES predicted patient adherence, little support was found that SES-based resources made respondents better or worse patients. Independent variables such as social support, social capital, faith in institutions, comfort in social situations, and participation in high-brow leisure activities did not predict patient adherence. The two main predictors of patient adherence in addition to SES were self-efficacy and whether or not the respondent smoked.

The most noteworthy finding from the statistical analysis was that an individual's father's education predicted adherence regardless of the individual's own educational attainment. While this finding does not contradict the resources theories described above, it does suggest that it is improbable that these resources are passed down through the father. The fact that individual's education, controlling for father's education, does not predict adherence suggests that the ability to be adherent is not learned through one's own individual schooling and cognitive training. Yet, it would be safe to speculate that attitudes are instilled in households that are stable, which provide the children in those families the means to be positive and efficacious about their health.

In the qualitative analysis based on 17 in-depth interviews, individuals from stable homes and from families where education was valued were generally more adherent to their treatment showing an acceptance that following the rules was self-evident. Individuals whose childhood had a degree of instability – whether it was parents who divorced, or parents that were not involved in

their children's lives – were much more likely to be depressed, to feel trapped in their current situation, and thus to struggle with aspects of their treatment.

Coinciding with the finding concerning father's education and adherence was that individual's occupation was a predictor of adherence. From the interviews, it became clear that individuals who had fulfilling careers tended to see dialysis as a situation to manage or deal with separately from the central meaningful things in their lives. Dialysis, for these respondents, was a "part-time job" as some stated, and had to be treated as if it were simply a task that needed to be done. Individuals whose conceptions of themselves did not follow from their identities as career-oriented people, did not have the same attitude toward their treatment or their illness.

What emerged from the self-observations was a visual non-adherence displayed entirely by middle-aged, working class men. During my six years of treatment, there were a handful of men who resisted the orders of their doctors publicly, ignored the rules of the hemodialysis facilities, and generally caused trouble. All of these men were habitually non-adherent, many to the point where they became very ill or died. It is hard to draw conclusions from these cases, but perhaps we can assume that these men have stories and pasts that fit well with the findings described in both the quantitative and qualitative sections.

### **Resources or Stable Environment?**

While there is no consensus in current sociological research in terms of how to theorize health disparities, there is a growing preference for conceptualizing health as an achieved status. In this sense, individuals invest resources in their own health (and, theoretically, in their children's health) as a conscious process. Fundamental cause theory, human capital theories, and cognitive theories provide rationalist explanations for health outcomes.

In terms of general health outcomes, these theories may be perfectly correct in their conceptualization. In terms of chronic illness, or more specifically those with chronic kidney disease, these "rationalist" theories seem to offer little in terms of how people handle their illnesses. Variables such as social support and social capital, as well as cultural capital (measured in a variety of ways) do not determine adherence to treatment. Instead, a self-efficacious attitude

when dealing with a troubling situation that requires a great deal of effort seems to derive from a disciplined, stable and supportive childhood.

Therefore, one could speculate that in terms of chronic illness, social-psychological approaches to understanding the relationships between SES and health are the most promising and appropriate. Some studies in the life course perspective (Morgan et al. 2012; Stewart-Brown, Fletcher and Wadsworth 2005) link the quality of early relationships between children and parents to health outcomes later in life for those children. While the Stewart-Brown et al. study does not explain the direct mechanism by which individuals either make poor health choices or are physiologically affected by early stress, it is an important example of research showing how negative psychological experiences are crucial in explaining one's life chances.

One of the limitation of this present study is that there is no evidence of a direct mechanism that links either father's education or individual's occupation to adherence. In both cases, there must be some (or multiple) mediating variable(s), when controlled for, washes away both the effects of father's education and individual's occupation. It is somewhat likely that these variables would be psychological in nature, and that both the early childhood environment and an individual's work environment would produce an underlying mode of consciousness that is well-suited for dealing with a challenging illness. Further qualitative analyses must identify a more comprehensive and rigorous link between these variables to provide a starting point for either using existing measures or creating new ones. Much more focused questionnaires with these new measures would need to be conducted with the goal of explaining SES/adherence relationships.

It is important to distinguish between general health outcomes for individuals and those who suffer from chronic illness. It may very well be true that the findings in this particular study – that early childhood experiences impact one's attitude about health in adult life – may only be applicable to chronic illness. Kidney failure and the subsequent need for dialysis presents individuals with a very challenging situation. Being a disciplined individual may not be enough when dealing with a long and rigorous treatment, but valuing one's own health and one's importance may give people the motivation to become disciplined and adherent. These attitudes are more likely to be very important when life becomes tortuously difficult, as opposed to the mundane disease preventing behaviors – diet and exercise – with which most individuals deal.

That is not to say that the findings of this study are non-generalizable. It is unclear what the potential is for approaching health disparities by looking at childhood experiences and the impact of occupation on health. Future studies on health disparities should pay attention to these variables when assessing health outcomes, whether they be epidemiological studies looking at broader health outcomes or research focusing on specific illnesses.

Going beyond the purview of medical sociology, the findings presented in this study may add to the understanding of how systems of inequality come about. As theorized in Chapter 7, adherence as a general term is applicable in a multitude of settings, whether they are health, education, the job market, occupation, intimate relationships, or crime and justice. Bourdieu rightly notes that success in a field depends on one's ability to have a "feel and knowledge" of the game one is playing. Modern institutions are complex and nuanced organizations that require a high degree of sophistication to navigate. But perhaps what makes individuals succeed in these "games" is not only the skills or "capitals" one has, but rather an acceptance of these institutions as right and good, and that in the end "adherence" to the rules is worthwhile and beneficial.

## Appendix A: Interview Guide

### Warm-up Questions

- How did you end up being on dialysis?
- What was the cause of your kidney problems?

### General Dialysis Coping

- What kinds of things are you having trouble with being on dialysis?

*If not stated above:*

- Do you ever have problems with any of the following:
  1. Fluids
  2. Phosphorous (including medication)
  3. Potassium
  4. Going to treatment/missing treatments
  5. Taking medication

*If they have problems with any of these:*

Why do you think you have a problem with X?

- What, if any, strategies do you use to deal with
  1. Fluids
  2. Phosphorous (including medication)
  3. Potassium
  4. Going to treatment
  5. Taking medication

Being on dialysis can be difficult financially. Does your income have anything to do with these problems?

### Class Background

- Was there anything about how you were raised that helps (or hurts) when dealing with dialysis?

### *Probes*

- What kind of family did you grow up in? Tell me about your parents.
- What kind of a student were you in school? Hard-working?

### **Caregiver Relationships**

- Do you think that the nurses or doctors have anything to do with how you are as a patient, or do you think it's solely your responsibility?
- Was there anything about how you were raised that helps (or hurts) when dealing with the nurses or doctors?

### *Probes*

- How well do you get along with your nurses?
- How well do you get along with your doctors?
- Do they ever bother you when they talk about how well you're doing as a patient, monthly blood-work and other things related to treatment?

### **Occupation**

- Is there anything about your job/career that helps you deal with dialysis?
- What kind of work do you/did you do?

### **Conscientiousness**

- Putting up with all of this stuff about dialysis requires a fair amount of conscientiousness. How conscientious of a person do you think you are?
- How would you assess yourself as a patient? What do you think makes you a good patient or not?





7) How often do you ask to be taken off the machine early?

- a. Never or rarely.
- b. Once a month.
- c. Once every 2 weeks.
- d. Once a week.
- e. Most of the time.

8) If you ask to be taken off early, how much of your treatment do you normally miss?

- a. Don't come off early.
- b. Less than 5 minutes.
- c. More than 5 minutes but less than 15 minutes.
- d. More than 15 minutes but less than 30 minutes.
- e. More than 30 minutes.

9) Which of these two strategies do you tend to use *more* when dealing with your dialysis regimen?

- a. *I respond to my symptoms.* (For example, if you drink too much fluid, you might feel fatigued and puffy. Therefore, you drink until you start feeling this way – you have responded to symptoms).
- b. *I set limits on my behavior.* (For example, you have sheet which lists the amount of fluids you are allowed during one day. Once you reach that limit, you cannot drink anymore – you have set a limit on your behavior).

16) To what extent do you believe your personal behavior led to your kidney failure?

- a. Not at all.
- b. A little bit.
- c. Somewhat.
- d. Quite a bit.
- e. It was totally my fault.
- f. Don't know/Not sure.

17) Do you ever feel upset when doctors or nurses talk to you about diet and fluid limitations?

- a. All the time.
- b. Most of the time.
- c. Sometimes.
- d. Never or very rarely.

18) Does it annoy you when people **tell** you what to do, instead of simply **suggesting a course of action**? For example, does it annoy you that one of the doctors or nurses tells you flat out not to eat chocolate? Or do you consider it more respectful for them to suggest to you that it may be a bad idea to eat chocolate because of your condition. Or does it not make a difference which way they communicate? On a scale of 1 to 7 (with 1 being not annoyed at all and 7 being really annoyed) to what extent do you get annoyed when people **tell** you what to do?

1      2      3      4      5      6      7

(Not annoyed at all)

(Really annoyed)

19) How much do you agree/disagree with the following statement?

When someone tells you that you can't have something that you enjoy, it makes you crave that thing more.

- a. Strongly agree.
- b. Agree.
- c. Disagree.
- d. Strongly disagree.

20) When you don't understand something, how often do you ask for more information?

- a. All the time.
- b. Most of the time.
- c. Sometimes.
- d. Very rarely.

21) Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do what is necessary to manage your condition on a regular basis?

1       2       3       4       5       6       7

(Not confident at all) (Totally confident)

22) How confident are you that you can reduce the emotional distress caused by your health condition so that it does not affect your everyday life?

1       2       3       4       5       6       7

(Not confident at all) (Totally confident)

23) How confident are you that you can do things other than just taking medication (exercise and diet, staying active, etc.) to reduce how much your illness affects your everyday life?

1       2       3       4       5       6       7

(Not confident at all) (Totally confident)

***Now I'd like to ask you some questions about your family, work, and past:***

24) What kind of work do you (did you) normally do? That is, what is (was) your job called? Also, tell me what type of place do you (did you) work for?

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25) How much education have you completed?

- a. Did not finish high school.
- b. High School diploma.
- c. Some college, but no degree.
- d. Two-year college degree.
- e. Four-year college degree.
- f. Advanced degree (e.g. Masters, PhD, MD, Law degree).

26) What kind of work did your father (male guardian) usually do when you were growing up? That is, what was his job called? Also, what type of place did he work at?

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27) How much education did he complete?

- a. Did not finish high school.
- b. High School diploma.
- c. Some college, but no degree.
- d. Two-year college degree.
- e. Four-year college degree.
- f. Advanced degree (e.g. Masters, PhD, MD, Law degree).

28) What kind of work did your mother (female guardian) usually do when you were growing up? That is, what was his job called? Also, what type of place did she work at?

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29) How much education did she complete?

- a. Did not finish high school.
- b. High School diploma.
- c. Some college, but no degree.
- d. Two-year college degree.
- e. Four-year college degree.
- f. Advanced degree (e.g. Masters, PhD, MD, Law degree).

In this next series of questions, I want you to tell me if you have a personal relationship (acquaintance/friend/relative), *not* a professional relationship, with anyone who has the following occupations. I would like to know the **number** of people you know for each occupation, and the **strength** of your relationship to those people.

30) How many people do you know that are?

Do you talk/see to some or all of these people often?

	(please circle)					(please circle)	
<b>Nurses</b>	0	1	2	3	4 or more	Yes	No
<b>School Teachers</b>	0	1	2	3	4 or more	Yes	No
<b>Skilled Laborers (carpenters, plumbers, bricklayers)</b>	0	1	2	3	4 or more	Yes	No
<b>Doctors</b>	0	1	2	3	4 or more	Yes	No
<b>Secretaries</b>	0	1	2	3	4 or more	Yes	No
<b>Managers</b>	0	1	2	3	4 or more	Yes	No
<b>Janitors/Cleaners</b>	0	1	2	3	4 or more	Yes	No
<b>Salesworkers</b>	0	1	2	3	4 or more	Yes	No
<b>Lawyers</b>	0	1	2	3	4 or more	Yes	No
<b>Scientists/Engineers</b>	0	1	2	3	4 or more	Yes	No

This next part will ask some questions about the kind of support you receive from a variety of different people.

31) To what extent can you count on your **family** for support in terms of:

	I can never count on them	Rarely can I count on them	Some of the time I can count on them	Most of the time I can count on them	I can always count on them
<i>General advice</i>	1	2	3	4	5
<i>Material aid</i> (food, Housing, transportation)	1	2	3	4	5
<i>Emotional support</i>	1	2	3	4	5

32) To what extent can you count on your **friends** for support in terms of:

	I can never count on them	Rarely can I count on them	Some of the time I can count on them	Most of the time I can count on them	I can always count on them
<i>General advice</i>	1	2	3	4	5
<i>Material aid</i> (food, Housing, transportation)	1	2	3	4	5
<i>Emotional support</i>	1	2	3	4	5

33) To what extent can you count on your **doctors** for support in terms of:

	I can never count on them	Rarely can I count on them	Some of the time I can count on them	Most of the time I can count on them	I can always count on them
<i>General advice</i>	1	2	3	4	5
<i>Material aid</i> (food, Housing, transportation)	1	2	3	4	5
<i>Emotional support</i>	1	2	3	4	5

34) To what extent can you count on your **nurses and other staff members** for support in terms of:

	I can never count on them	Rarely can I count on them	Some of the time I can count on them	Most of the time I can count on them	I can always count on them
<i>General advice</i>	1	2	3	4	5
<i>Material aid</i> (food, Housing, transportation)	1	2	3	4	5
<i>Emotional support</i>	1	2	3	4	5

35) To what extent can you count on your **other patients** for support in terms of:

	I can never count on them	Rarely can I count on them	Some of the time I can count on them	Most of the time I can count on them	I can always count on them
<i>General advice</i>	1	2	3	4	5
<i>Material aid</i> (food, Housing, transportation)	1	2	3	4	5
<i>Emotional support</i>	1	2	3	4	5

36) What is the *total amount* of income made last year in the house in which you currently live in (how much did everyone who lives there make combined)?

- |                                     |                                     |
|-------------------------------------|-------------------------------------|
| a. \$20,000 or less.                | f. Between \$120,001 and \$140,000. |
| b. Between \$20,001 and \$40,000.   | g. Between \$140,001 and \$160,000. |
| c. Between \$40,001 and \$60,000.   | h. Between \$160,001 and \$180,000. |
| d. Between \$60,001 and \$80,000.   | i. Between \$180,001 and \$200,000. |
| e. Between \$80,001 and \$100,000.  | j. More than \$200,001.             |
| f. Between \$100,001 and \$120,001. | k. I don't know.                    |

37) Have you ever taken a mortgage loan for a house?

- a. Yes
- b. No

38) How comfortable do (did) you generally feel:

	Very Comfortable	Somewhat comfortable	Somewhat uncomfortable	Very uncomfortable	Don't know/ Not applicable
In job interviews?	1	2	3	4	5
Applying for a loan?	1	2	3	4	5
Asking doctors questions?	1	2	3	4	5
Speaking in public?	1	2	3	4	5
Talking to police?	1	2	3	4	5
Dealing with teachers when you were a student?	1	2	3	4	5

39) How confident are you in these social institutions are in the United States?

	Very confident	Somewhat confident	Neither confident or unconfident	Somewhat unconfident	Very unconfident
Educational system	1	2	3	4	5
Healthcare system	1	2	3	4	5
Legal system/Police	1	2	3	4	5
National Government	1	2	3	4	5
State Government	1	2	3	4	5
Religious Institutions	1	2	3	4	5
Banks	1	2	3	4	5

40) *During your lifetime*, how often have you participated in the following activities? Also, please check the box to the left of the item if you still participate in these activities.

(Still participate) Check	Often	Sometimes	Rarely	Never	Not sure
<input type="checkbox"/> Sailing	1	2	3	4	5
<input type="checkbox"/> Golfing	1	2	3	4	5
<input type="checkbox"/> Skiing	1	2	3	4	5
<input type="checkbox"/> Bowling	1	2	3	4	5
<input type="checkbox"/> Going to the gym	1	2	3	4	5
<input type="checkbox"/> Reading classical literature	1	2	3	4	5
<input type="checkbox"/> Racquetball	1	2	3	4	5
<input type="checkbox"/> Bingo	1	2	3	4	5
<input type="checkbox"/> Fishing	1	2	3	4	5
<input type="checkbox"/> Going to a museum	1	2	3	4	5
<input type="checkbox"/> Attending a classical music concert	1	2	3	4	5
<input type="checkbox"/> Going to the opera	1	2	3	4	5
<input type="checkbox"/> Participating in a voluntary or civic association	1	2	3	4	5
<input type="checkbox"/> Going to church/mosque/synagogue	1	2	3	4	5

Instructions: The following questions consist of a group of 14 questions. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, **circle the highest number** for that group. Be sure that you do not choose more than one statement for any group.

41)

- 0 I do not feel sad
- 1 I feel sad much of the time
- 2 I am sad all the time
- 3 I am so sad or unhappy that I can't stand it

42)

- 0 I am not discouraged about my future
- 1 I feel more discouraged about my future than I used to be
- 2 I do not expect things to work out for me
- 3 I feel my future is hopeless and will only get worse



- 43)
- 0 I do not feel like a failure
  - 1 I have failed more than I should have
  - 2 As I look back, I see a lot of failures
  - 3 I feel I am a total failure as a person
- 44)
- 0 I get as much pleasure as I ever did from the things I enjoy
  - 1 I don't enjoy things as much as I used to
  - 2 I get very little pleasure from the things I used to enjoy
  - 3 I can't get any pleasure from the things I used to enjoy
- 45)
- 0 I don't feel particularly guilty
  - 1 I feel guilty over many things I have done or should have done
  - 2 I feel quite guilty most of the time
  - 3 I feel guilty all of the time
- 46)
- 0 I don't feel I am being punished
  - 1 I feel I may be punished
  - 2 I expect to be punished
  - 3 I feel I am being punished
- 47)
- 0 I feel the same about myself as ever
  - 1 I have lost confidence in myself
  - 2 I am disappointed in myself
  - 3 I dislike myself
- 48)
- 0 I don't criticize or blame myself more than usual
  - 1 I am more critical of myself than I used to be
  - 2 I criticize myself for all of my faults
  - 3 I blame myself for everything bad that happens
- 49)
- 0 I don't have any thoughts of killing myself
  - 1 I have thoughts of killing myself, but would not carry them out
  - 2 I would like to kill myself
  - 3 I would kill myself if I had the chance
- 50)
- 0 I don't cry anymore than I used to
  - 1 I cry more than I used to
  - 2 I cry over every little thing
  - 3 I feel like crying, but I can't

- 51)
- 0 I am no more restless or wound up than usual
  - 1 I feel more restless or wound up than usual
  - 2 I am so restless or agitated that it's hard to stay still
  - 3 I am so restless or agitated
- 52)
- 0 I have not lost interest in other people or activities
  - 1 I am less interested in other people or things than before
  - 2 I have lost most of my interest in other people or things
  - 3 It's hard to get interested in anything
- 53)
- 0 I make decisions about as well as ever
  - 1 I find it more difficult to make decisions than usual
  - 2 I have much greater difficulty in making decisions than I used to
  - 3 I have trouble making any decisions
- 54)
- 0 I do not feel I am worthless
  - 1 I don't consider myself as worthwhile and useful as I used to
  - 2 I feel more worthless as compared to other people
  - 3 I feel utterly worthless

***Now, here are some questions about your background:***

55) How old are you?

\_\_\_\_\_

56) What is your sex?

- a. Female
- b. Male

57) Do you smoke?

- a. Yes
- b. No

58) What is your ethnic background?

- a. Hispanic
- b. Black
- c. White
- d. Asian
- e. Other \_\_\_\_\_

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