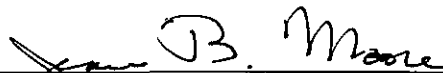
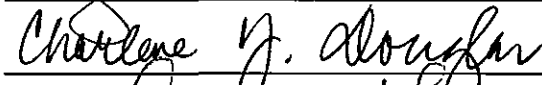

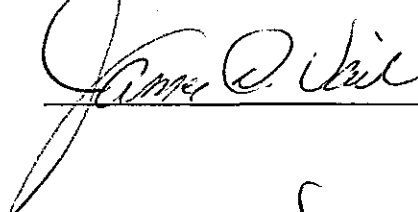



SHIFTING LIFE'S FOCUS: AFRICAN AMERICAN DIALYSIS PATIENTS'  
EXPERIENCES WITH KIDNEY TRANSPLANT EVALUATION

by

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A Dissertation  
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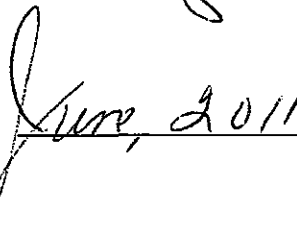
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## DEDICATION

This is dedicated to the ten participants who shared their beliefs, hopes, concerns, and a part of their lives with me in hopes of helping clinicians better understand them and their illness experiences. Their honesty, wisdom and caring touched me deeply, and motivated me to speak for them through this study.

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## ABSTRACT

### SHIFTING LIFE'S FOCUS: AFRICAN AMERICAN DIALYSIS PATIENTS' EXPERIENCES WITH KIDNEY TRANSPLANT EVALUATION

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George Mason University, 2011

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Chronic kidney disease is a growing health problem that, in the United States, disproportionately affects African Americans. Although African Americans have a significantly higher incidence of kidney disease and end stage kidney failure than Caucasian Americans, they are less likely to receive a kidney transplant. This study begins to build a substantive theory about patients' experiences with the kidney transplant evaluation process to better understand this health disparity. Participants in this study were interviewed in the dialysis unit about these experiences.

*Shifting Life's Focus*, the substantive theory emerging from this study, explains participants' experiences with the process of kidney transplant evaluation as they physically and emotionally prepared to receive a kidney transplant. Three major concepts compose this theory: complex chronic health issues, financial concerns, and following through. This theory not only explains the experiences of these participants, but may help explain those of other African American patients on dialysis. Understanding

this theory may provide insight to reasons why many African Americans may not complete their transplant evaluations and be listed to receive a kidney transplant, and therefore has direct application to both health policy and clinical practice.

## 1. INTRODUCTION

Chronic kidney disease (CKD), a global public health problem, affects approximately 26 million people in the United States (U.S.) (United States Department of Health and Human Services [USDHHS], 2007). CKD eventually leads to kidney failure—also called end stage renal disease (ESRD)—which, in turn, results in death unless treated with chronic dialysis or kidney transplantation. Kidney transplantation, the preferred method of treatment for those with kidney failure, is not available to everyone due in part to the growing shortage of kidneys available from a deceased or living donor. Additionally, transplantation may not be available to a patient with kidney failure because of lack of access to transplantation, health complications that preclude transplantation, sociocultural issues that exclude the patient from transplantation, or an inability to complete the complex transplant evaluation process. However, the contribution of the patient self-decision process has not been explored. Is it possible, that, although transplantation is the preferred choice of therapy, some patients do not choose to receive a transplant because of concerns or beliefs that are not directly expressed?

### **Background and Significance**

Racial disparities in CKD and kidney transplantation have been well documented. Specifically, when compared to Caucasian Americans, African Americans have

disproportionately high incidences of risk factors causing chronic kidney disease, but a decreased frequency and rate of referral for transplantation, higher numbers of patients who do not complete their transplant evaluation, and fewer overall kidney transplants (Agency for Healthcare Research and Quality [AHRQ], 2004; Epstein et al., 2000). Indeed, although the incidence of kidney failure is higher in African Americans than in Caucasian Americans, African Americans constitute just 38% of the national kidney transplant waiting list, and receive only 28% of deceased donor kidneys (Young & Kew, 2005). Additionally, African Americans receive living donor transplants less often than Caucasian Americans (Young & Kew, 2005).

Research on the disparities in prevalence, causes, and treatments related to African Americans with CKD and kidney transplantation, which has primarily been quantitative in nature, continues to focus on determinants of health, i.e., genetic and environmental factors, socioeconomic factors, racial and ethnic discrimination, and behavioral factors. Though helpful in identifying current and growing health disparities, the information gained from quantitative research does not fully explain this complex issue. Thus, a qualitative study detailing patients' actual experiences and uncovering the way in which these experiences influence the decision to complete a transplant evaluation provides new knowledge—and a theoretical framework—for a more complete understanding of racial disparities in kidney transplantation.

## **The Problem**

The rising number of African American kidney failure patients and growing disparity of renal transplantation between Caucasian American and African American patients leads to many questions. Are there aspects of the referral and evaluation process that prevent African American patients from completing the transplant evaluation? Do African American patients referred for kidney transplantation desire to be a kidney transplant recipient and what obstacles do they encounter in the achievement of that goal?

### **Statement of Purpose**

The purpose of this research study was to generate a grounded, substantive understanding of the experiences that African American dialysis patients have during evaluation for kidney transplantation. From this understanding, a theoretical framework was developed which will provide a basis for future research into how these experiences influence their decision to complete the transplant evaluation. This framework can help guide an interdisciplinary approach to transplant referral, evaluation, and patient/community education for the care of African American patients with CKD in dialysis units, transplant centers, and the community.

### **Research Questions**

The research problem, or substantive area of focus, is the experience of African American dialysis patients undergoing a kidney transplant evaluation. The initial research questions, broadly stated below, became more narrowly focused during the research process as the concepts developed.

What are the concerns of African American chronic kidney disease patients undergoing evaluation for kidney transplantation?

How do these concerns account for their experiences during the transplant evaluation or affect their ability to complete the transplant evaluation?

### **Framework**

The research questions lead to using an inductive, grounded theory approach, both in terms of the method of inquiry and the mode of analysis. Applying grounded theory methods of interview and observation to the substantive area of African American dialysis patients undergoing evaluation for kidney transplantation allowed the researcher to gather rich data in the process of exploring the participants' lived experiences. Methods as described by Strauss and Corbin (1998) are used throughout this study to analyze the data and develop theory in order to answer the research questions.

## 2. LITERATURE REVIEW

The goal of this study was to explore one aspect—the experiences of patients undergoing transplant evaluation—of a growing disparity in the rate of kidney transplantation in African Americans. Here a step has been taken toward generating a theoretical framework for understanding the experiences of African Americans undergoing kidney transplant medical evaluation, an essential requirement for receiving a transplanted kidney.

An initial literature review was conducted to identify prior research on health disparities in CKD and kidney transplantation. Using the grounded theory methods of Strauss and Corbin (1998), a second literature review was performed to explore the theoretical concepts as they emerged during the analysis of interview data. However, the complete picture of health disparities in CKD and renal transplantation in African Americans is complex and continues to receive focused study.

In the initial literature review, the Cochrane, Medline, CINAHL, and Dissertation Abstracts databases were searched using the terms health disparities, African American, kidney disease, chronic kidney disease, end stage renal disease, kidney transplantation, racial differences, race, kidney failure, and transplantation. In grounded theory, the literature is researched a second time, focusing on the developed concepts. The second literature search, using the same databases, focused on the following additional terms:



transplant evaluation, poverty, socioeconomic status, dialysis, hemodialysis, Medicare, diabetes, and obesity.

Some of the earliest health disparities literature originated in the mid-1990s in the area of cardiovascular care (Institute of Medicine [IOM], 2003). These early studies prompted the U.S. Congress to request an IOM study “to assess disparities in the kinds and quality of healthcare received by U.S. racial and ethnic minorities and non-minorities” (IOM, 2003, p.30). The report, first published in 2002, contained a comprehensive review of the literature, analysis of the problem, and recommendations for action. Further, included in this report, Unequal Treatment, was a focus on health disparities in renal transplantation. In the years since the initial publication, the incidences of CKD and ESRD have rapidly grown.(USRDS Annual Data Report, 2010)

For the organization of this chapter, reporting of the literature will be divided into three subsections: 1. Chronic kidney disease in African Americans; 2. Renal transplantation in African Americans; and 3. Socio-cultural and environmental factors related to health disparities in CKD and renal transplantation of African Americans.

### **Chronic Kidney Disease in African Americans**

Following studies of the 1980s detailing the alarming growth of renal disease and associated costs in the U.S., several large, nationally-based programs were developed to understand and prevent this growing public health problem and the inequities in the care of affected African Americans. The National Kidney Foundation (NKF) initiated two specific programs for screening and prevention: The Kidney Early Evaluation Program (KEEP) pilot program and the Computerized Assessment of Risk and Education (CARE)

program. The KEEP pilot program was initially organized around the 21 clinical centers in the National Institute of Health (NIH) African American Study of Kidney Disease and Hypertension (AASK). These programs and the KEEP 2000 program, which addresses coalition building and professional education in addition to individual and community education, are summarized by Vassalotti et al. (2009). Because this is a volunteer, self-selected population, the participation of African Americans in KEEP is almost four times greater than the sample population in the National Health and Nutrition Examination Survey (NHANES). Vassalotti describes the resulting data from this long term project in terms of the demographics and co-morbidities associated with renal disease and concludes that the limitations include the following:

In addition to being enriched for CKD, self selection bias of the volunteer KEEP population compared with the general NHANES population shows the former to be older, with greater proportions of woman and African Americans, higher levels of education, and participants presumably more highly motivated. (Vassalotti et al., 2009, p.108)

Importantly, the KEEP program data have fueled many of the current studies in this field.

The National Institutes of Health initiated the AASK study as the first large cohort study of African Americans with kidney disease. Sika et al. (2007) prospectively studied a cohort of these participants over four years to track blood pressure and standardized treatments and identify additional risk factors. They found that, despite well-controlled blood pressure in the subjects, kidney disease progressed. Buckalew (2010) also used the AASK and NHANES data and compared these with data from the Reasons for

Geographic and Regional Differences in Stroke (REGARDS) data to address racial differences in kidney failure, disease progression, and mortality on dialysis. The results of that study indicate that African Americans develop kidney failure earlier than Caucasians; however, African Americans on dialysis show better survival than Caucasians presumably because of less cardiovascular disease. This advantage persists even when the sample is adjusted for age, co-morbid conditions, and socioeconomic conditions. Buckalew explained that a genetic variant (*MYH9* gene) in African Americans may influence the development of kidney disease and the lack of related cardiovascular disease and death from cardiovascular complications.

Fueled by data indicating a parallel in the increase in rates of obesity and metabolic syndrome and that of CKD, Bombeck (2010) used KEEP data to study a cohort of over 37,000 obese African American and Caucasian participants to examine the co-morbidity of obesity in renal disease. This study found that obesity itself (independent from other risk factors) has a role in CKD development, one that differs between African Americans and Caucasians.

Additional risk factors for CKD were analyzed by Powe and Melmed (2005), who studied the risks of diabetes and obesity in African Americans. Diabetes is the most common cause of ESRD in the U.S. and is a disease that disproportionately affects African Americans: African American women have 2.4 times the risk of having diabetes than Caucasian American women, and African American men have 1.5 times the risk of having diabetes than Caucasian American men. In addition, African Americans with type 2 diabetes have a higher risk of developing ESRD than Caucasian Americans with type 2

diabetes. Further, CKD is associated with obesity. Fifty percent of African American women are obese (BMI > 30), compared with 30% of Caucasian American women. (Powe & Melmed) In a prospective, observational follow-up study of participants in the AASK trial, Toto (2010) examined the association between obesity and CKD markers (proteinuria). The results indicate an association between BMI and proteinuria; however, a causal link could not be established.

Gadegbeku et al. (2005) analyzed health disparities affecting African Americans in the pathophysiology and management of hypertension, one of the leading causes of renal failure in the U.S. In addition to physiological differences in salt sensitivity and angiotensin system activity compared with Caucasian Americans, this study reported that African Americans suffer earlier onset and higher prevalence and severity of hypertension than any other ethnic group. Additionally, this population suffers a two-fold incidence of stroke, four times the prevalence of hypertensive nephropathy, and 50% higher mortality from heart disease. The authors concluded that the mechanisms underlying the severity of hypertension and its sequelae in African Americans is believed to be multifactorial. Okonofua et al. (2005) studied other contributors to the excess cardiovascular and renal morbidity and mortality seen in African Americans. These authors concluded that factors that influence the prevalence and control of hypertension include compliance to prescribed interventions such as medication and lifestyle modifications, social support, education interventions, and intensity of therapy.

The literature shows the developing specificity in the exploration of kidney disease in African Americans. The funding of many large, national studies has provided a

growing amount of data that are being analyzed from various perspectives. Additionally, genomic research providing new information about genetic differences in kidney disease is beginning to shed light on health disparities in African Americans with kidney disease. Recent health disparities research reflects the perspective of minority researchers (e.g., Crews, Calendar, and Powe), which improves the depth of understanding that can be presented analytically; however, all of this research is quantitative in nature.

### **Renal transplantation in African Americans**

Due to the high incidences of diabetes and hypertension in African Americans, many have chronic or end stage renal disease and are potential candidates for renal transplantation. The IOM study, citing literature prior to 2002 in a separate section on disparities in transplantation, indicates that African Americans, who constitute 12% of the U.S. population, represent almost one-third of those with ESRD (IOM, 2003). Young and Kew (2005), citing United States Renal Data Statistics (USRDS) for 2003, reported the incidence of ESRD in whites as 334 per million as compared to African Americans, with 998 per million. However,

[a]lthough kidney transplantation is the preferred renal replacement solution for those who qualify to be placed on the waiting list due to improved survival and less cost over time, African Americans are not activated on the list at the same rate as whites. (Powe & Melmed, 2005, p.484)

Indeed, although the incidence of ESRD is so much higher in African Americans than Caucasian Americans, African Americans only constitute 38% of the national waiting list, and receive less than 28% of deceased donor kidneys (Young & Kew, 2005).

The beliefs of both doctors and patients seem to influence this disparity. The referral patterns of nephrologists indicate that nephrologists are less likely to believe transplant improves survival for African Americans as much as whites, even though they believed that kidney transplantation improves quality of life equally (Young & Kew, 2005). Ayanian et al. (1999) looked at the effect of patient preferences on racial differences in access to transplantation by studying a large sample of dialysis patients in four different regions of the country. They reported several disparities between African American and Caucasian American dialysis patients, including the following: black patients were less likely to want a transplant and to expect their quality of life to improve with one; and blacks were less likely than whites to report that their primary nephrologists provided all the medical information they desired, that they agreed with this doctor, and that they trusted this doctor's judgment about their medical care. Among patients who wanted a transplant, blacks remained significantly less likely than whites to have been referred for evaluation and significantly less likely to be placed on a waiting list or to have received a transplant within eighteen months of starting dialysis (Ayanian et al., 1999).

In another study of barriers to transplantation, over 9,000 patients referred for transplant in Indiana, Kentucky, and Ohio were studied prospectively over a four-year period (Alexander & Sehgal, 1998), assessing the steps in the evaluation process to get on the deceased donor waiting list in that region of the country. Substantial differences in the evaluation process highlight the role of the pre-transplant evaluation and medical workup as a barrier to transplantation access. Patients who were African American were

less likely than Caucasians, women, and lower-income individuals to complete the transplant evaluation process. Additionally, age, diabetes, and years on dialysis prevented patients from completing their evaluation (Alexander & Sehgal, 1998). Importantly, as the number of African Americans with kidney failure increases, these health disparities persist.

The Dialysis Outcomes and Practice Patterns (DOPPS) study is a prospective, observational, international study that describes variations in wait listing (being placed on a national waiting list for a kidney transplant) and kidney transplantation in nationally representative samples of patients (Satayathum et al., 2005). In the U.S., wait listing is lower for African American dialysis patients than Caucasian dialysis patients, a finding the authors corroborated by assessing the Scientific Registry of Transplant Recipients (SRTR) data. These data also confirmed that, independent of income and education, blacks are less likely than whites to receive a transplant (Satayathum et al., 2005). Additionally, the DOPPS study showed that patients, regardless of race, who had less than three years of dialysis have approximately twice the rate of getting a transplant as patients with six years of dialysis or more.

Weng (2005) also looked at factors that prevented patients from completing their transplant evaluation and medical workup to discover whether failure to complete the evaluation accounts for decreased access to transplantation among African American patients in one transplant center in Pennsylvania. This observational, prospective cohort study of 175 patients reported several important findings. In the descriptive analysis, “patients on dialysis at the time of their transplant evaluation were more likely to be

black, lack a college education, report disability or unemployment, have lower household income, and list Medicare as their medical insurance” (Weng, 2005, p.736) than patients not on dialysis. Further, analysis of the time to completion of the transplant evaluation indicated that black race was significantly related to a decrease in the rate of completion of the transplant evaluation.

While research from the transplantation field begins to become more specific in terms of quantifying access to treatment (transplantation) for African Americans, once again these studies are quantitative in nature. Additionally, although the transplant physicians and researchers may be studying these concerns in an attempt to advocate for their patients, the perspective of the patients has not been addressed.

### **Social-cultural and Environmental Factors Related to Health Disparities in CKD and Renal Transplantation in African Americans**

Ongoing research related to African American patient access to kidney transplantation consistently affirms that the causes of health disparities are complex and not yet fully described. Socio-cultural and environmental factors are believed to play a part in the development of these disparities. This section of the literature review will be divided into the following sub-headings for clearer presentation: Racism and stress; Coping and mistrust; Quality of life; and Socioeconomic status, social class, and social support.

**Racism and Stress** Much of the behavioral analysis of health practices of African Americans has been built on a foundation of the contribution of life experiences and socio-demographic factors shaping health care attitudes. Anthony (1998) explained that



cultural learning related to the history of racism, segregation, and discrimination has resulted in passive health care behaviors in African Americans. This same concept is discussed by Williams and Jackson (2005) who stated that the “subjective experience of discrimination is a neglected stressor that can adversely affect the health of African Americans” (p. 328). Their conclusion on social factors in the environment that initiate and sustain racial disparities in health was that “disadvantaged groups and those with low socioeconomic status are less likely to reduce high risk behavior or to initiate new health-enhancing practices” (p.331).

Similar reasoning is described by Bruce et al. (2009). In a review of the literature related to health disparities in the social science and social epidemiology fields, the researchers explained that racism and institutionalized racism are stressors associated with the social environment of many African Americans. Because of living environments with repeated exposure and interactions that are experienced as being discriminatory, a physiological response, such as elevated blood pressure, is elicited. Therefore, the authors concluded that racism and discrimination can adversely affect CKD progression and its complications (Bruce et al., 2009, p.584).

More specifically, Klassen et al. (2002) studied the perceptions of discrimination in transplant-eligible African American and Caucasian American dialysis patients and found that perceived discrimination influenced whether or not patients were on the kidney transplant waiting list. Those patients who perceived that they had experienced either sexual or racial discrimination were less likely to be actively listed for a kidney transplant. The authors summarized that

repeated experiences of disadvantage leave victims with fewer social and economic resources across their entire lives. The accompanying psychological effect, in our opinion, is that victims of discrimination learn to anticipate poorer outcomes than advantaged members of society, and thus become reluctant to enter into situations which they expect to be treated unfairly.

(Klassen et al., 2002, p.816)

**Coping and Mistrust** Several studies have focused on differences in coping styles and effectiveness between African Americans and Caucasian Americans. In a study of white and black ESRD patients needing a kidney transplant, Lunsford et al. (2005) found that African Americans are more likely than non-African Americans to deny the need for transplant and are less accepting of their situation. Further, Okonofua et al. (2005) found that “despite the findings that African Americans were more knowledgeable about the definition, etiology, and consequences of hypertension, their lower reliance on lifestyle modifications to control their hypertension is of concern in view of their higher prevalence and lesser access to medications.” (p.977)

Interestingly, Cort (2004) described that cultural mistrust in health care is believed to be unique to African Americans. In one regional qualitative study in Nashville, in which groups of African Americans participated in focus groups, one of the predominant themes identified was the lack of trust in the health care system and/or physicians (Miller, 2001). Similarly, in an extensive analysis of racial disparities in the delivery of chronic renal disease care, Powe and Melmed (2005) observed that minority groups lack trust in providers and related this finding to the history of discrimination as well as unethical

research experimentation in the past. Further, Powe and Melmed (2005) cited that risk factors for CKD are under-managed in African Americans due to limited access to appropriate care providers as well as ineffective communication between African American patients and health care providers. Differences in language usage and culture are likely contributing factors leading to these communication problems that interfere with access and adequate risk factor management.

**Quality of Life** Quality of life (QOL) was explored in two separate studies of African American renal failure patients. Porter (2010) used the African American Study of Kidney Disease and Hypertension Cohort (ASK) study data and a variety of QOL measurement tools to study the Health Related Quality of Life (HRQOL) of African Americans with hypertensive CKD and found that lower income and unemployment were associated with lower HRQOL. In the second study Greene (2005) looked at QOL of different age groups of African American dialysis patients and found that the QOL of life of these patients steadily increased as they aged. This study suggests that patients become more comfortable with and/or accepting of their health and social status as they age. In the same study (Greene, 2005) the youngest patients consistently perceived their QOL to be the lowest.

**Socio-economic Status, Social Class, and Social Support** Although most QOL studies include a component of economic QOL, socio-economic status (SES) has been specifically analyzed in terms of its relationship with CKD and health disparities. SES measurements generally include family income and educational achievement. However, additional relationships have been analyzed, including social support and social class.

The relationship between low SES and kidney disease is reinforced in various studies. Crews (2010) studied the effect of low SES independent of race in Baltimore, where the annual incidence of ESRD is greater than 1,000 per million persons. SES in this study was defined using self-reported annual household income. Examining data from the Healthy Aging in Neighborhoods of Diversity Across the Lifespan (HANDLS) study, Crews found that low SES is related to CKD in blacks but not whites. Indeed, in the study of barriers to transplant evaluation completion by Alexander and Sehgal (1998), one of the significant findings was that the poor were less likely to finish their transplant evaluation. Bruce (2009) suggests that “the excess risks for chronic diseases such as CKD among groups such as African Americans are a function of economic deprivation” (p.584).

In an analysis of a large (12,631) subset of the Atherosclerosis Risk in Communities (ARIC) study, Shoham et al. (2007) explored whether or not individual social class (measured with a five-item questionnaire), educational level, or area-level socioeconomic resources are related to increased risk of CKD. These authors argue that social class is superior to SES measurement because class uses power relationships to explain how inequalities are generated and maintained.

In a study using focus groups, Schaeffer (2008) explored the relationship of educational level as a determinant of access to kidney transplantation and found that college graduates were three times more likely to get on the kidney waiting list than those patients with only a high school degree. Gadegbku et al. (2005) studied the relationship of low SES with hypertension and found that low SES is linked with increased stress,

poor nutrition, obesity, and increased tobacco and alcohol use. The authors stated that all of these aspects have a cumulative effect in leading to hypertension, and pointed out that one in four African Americans lives below the poverty level, as compared to one in twelve Caucasian Americans.

Social and environmental stress and the relationship with health behaviors and outcomes have been studied extensively in the African American dialysis and transplant population. Bruce et al. (2009) refer to the developing field of psychosocial aspects of nephrology as “psychonephrology.” Believing that the social environment is an important but overlooked aspect that contributes significantly to the unexplained incidence and progression of kidney disease, psychonephrology

draws heavily from the social science and social epidemiological literature to illustrate how exposure to social environmental stressors (e.g., poverty and discrimination) can adversely affect psychological functioning and prompt responses in the nervous and vascular systems that place individuals at a greater risk of CKD progression and complications.” (p.583)

In this paper, the authors presented a model showing the hypothesized associations between the social environment, psychosocial factors, behavioral factors, CKD risk factors, and CKD progression and complications, underlining the complex interactions involved in CKD (Bruce et al., 2009).

The literature review reveals that socioeconomic and environmental factors have an effect on the prevalence of kidney disease, ESRD, and access to kidney transplantation. However, these studies continue to explore these aspects from the perspective of the

researcher and not the patient. Results of the review of the literature demonstrate a lack of research from the patient's perspective.

### **Summary**

CKD and ESRD represent a heavy burden upon African American patients. The expanding research regarding kidney failure in African Americans implicates genetic and physiological factors as well as aspects of the social environment and personal factors in the development and progression of disease. Similar to the causes of kidney disease, the causes of barriers to kidney transplantation for African Americans are surely also multifactorial. Defining the barriers to kidney transplantation for African Americans will require many unique approaches of investigation.

Because of the lack of research of patients' actual beliefs and experiences in this area of study, knowledge generated to date is limited in its perspective. Research in the area of health disparities needs to further explore the beliefs and experiences of those patients involved to understand how their beliefs impact their care.

The grounded theory approach used in this study seeks to understand the experiences of the transplant evaluation process from the patients' perspectives to identify a framework for understanding the complexities underlying barriers to kidney transplantation.

### 3. METHODOLOGY

This chapter will be presented in the following sections: Design, Study Setting, Sample, Human Subjects Protection, The Transplant Evaluation Process, Data Collection, Data Analysis, Data Integrity.

#### **Design**

This grounded theory study was conducted to gain knowledge and understanding about one aspect of health disparities in kidney transplantation of African Americans. In grounded theory, the research question is discovered by systematically collecting and analyzing data to build middle-range theoretical frameworks that explain the collected data (Denzin & Lincoln, 2000). The aspect of study, or phenomenon being explored here, is the experience of the kidney transplant evaluation.

From the beginning, adherence to grounded theory procedures as described by Strauss and Corbin (1998) were followed. Grounded theory design allowed the researcher to collect data from the patient's experiences using interviews and observations, through open ended and semi-structured questions to explore the research questions. Using the theoretical perspective of symbolic interactionism, these interviews focused on the processes through which the participants create meanings (Charmaz, 2010).

Using this approach to develop a theoretical model explaining the experiences

encountered by participants during this phase of their illness will add to the body of knowledge currently known about access to transplantation for African Americans.

### **Setting**

This study was conducted in three different community-based chronic dialysis units, owned by a national dialysis company. In this east coast city, dialysis patients who are in need of a kidney transplant may be referred to one of two university affiliated medical center hospital transplant programs. The Medical Directors and dialysis staff collaborated with the researcher throughout the study regarding Institutional Review Board (IRB) application, referral of participants, and coordination of scheduling. All of the Medical Directors of the three participating dialysis units were nephrology faculty at one university hospital. All of the participants in the study were in the process of transplant evaluation at that same hospital's transplant center.

### **Sample**

A purposive sample of volunteers enrolled in this study included ten adult African American chronic dialysis patients. A description of the study participants is presented in Table 1. Two participants were from the first dialysis unit (unit A), four were from the second unit (unit B), and four were from the third unit. Each of the participants had regularly-scheduled dialysis treatments three days a week. Length of each dialysis treatment was around four hours. With the exception of one participant who received treatment in an isolation room, all received their treatment in the open unit in reclining chairs within six to eight feet of the next patient on either side. All interviews were



carried out between September 24, 2010 and February 17, 2011 in the dialysis units while the patients were receiving their dialysis treatments.

The sample was comprised of five women and five men who had been on dialysis for an average of seven years. Two participants had only been on dialysis two and a half years (the shortest time). The longest time any of the ten participants had been on dialysis was thirteen years. All of the participants were covered by Medicare as their primary health insurance due to the length of time they had been on dialysis. Two reported a family income of \$25-50,000/year, and the rest reported that their combined family income was less than \$25,000/year. Formal education completed ranged from 6<sup>th</sup> grade to some college. Of the ten patients, four had completed high school, the rest had not.

Prior to the interviews, participants self-reported demographic information on a demographic questionnaire (see Appendix F). Thus, all demographic information is from these questionnaires and has not been validated by the researcher.

**Table 1. Description of Study Participants**

Name	Gender	Age (Years)	Years on dialysis	Education	Insurance	Combined family income
Sam	Male	39	6	Some HS	Medicare and MA	<\$25,000/yr.
Tom	Male	52	6	Completed HS	Medicare and MA	<\$25,000/yr.
David	Male	64	7	Some college	Medicare and private insurance	\$25,000-\$50,000/yr.
Pam	Female	52	2.5	6 <sup>th</sup> grade	Medicare and MA	<\$25,000/yr.
Shirley	Female	59	9	Completed HS	Medicare and MA	<\$25,000/yr.
Jennifer	Female	52	2.5	Some HS	Medicare	<\$25,000/yr.
Larry	Male	55	10.5	Some HS	Medicare and MA	<\$25,000/yr.
Beckett	Male	44	13	Some college	Medicare and MA	<\$25,000/yr.
Sarah	Female	59	3.5	Some HS	Medicare	<\$25,000/yr.

HS= High School    MA=Medicaid (Medical Assistance)

### **Human Subjects Protection**

Study approval was requested and received through the George Mason University HSRB, the Medical Center Hospital's IRB, and the dialysis company's IRB (Appendices I, H and D respectively). The researcher had received letters of approval stating their agreements in participation from the Medical Directors of each of the three dialysis units. Prior to the referral of study participants, the researcher met with each dialysis unit's staff to discuss the study and share the consent forms. Each dialysis unit identified the staff member who would be the researcher's main contact during the study and would identify and refer potential participants to the researcher. Although a poster to solicit participants was developed and approved (Appendix E), it was not used in any of the dialysis centers. All referrals to participate came directly from the dialysis staff to the researcher verbally or by email contact.

The dialysis staff member identified potential candidates for the study and notified the researcher when the patient agreed to be contacted to discuss the study. The researcher reviewed the informed consent with each participant and obtained a signed form. Participants were informed that the brief survey and initial interview would take about an hour of their time, and that the second interview would be scheduled at their convenience, approximately one month following the first interview. Participants were also informed that they would be audiotaped only with their approval. If a participant did not want to be audiotaped they could still participate in the study, and the researcher would take notes. During the consent process, the researcher also discussed "member checking" with the participants. Participants were told that they would be asked to

review, comment on, and discuss the transcribed interviews to make sure that the researcher had accurately documented their words and their stories.

### **The Transplant Evaluation Process**

The kidney transplantation process involves a series of steps, beginning with the evaluation process. During the transplant evaluation, each patient is evaluated by a multi-disciplinary team to assess their medical and socioeconomic suitability to receive a kidney transplant.

**Referral** Referral to the transplant program for evaluation may be made directly by the patient or concerned family member, dialysis unit, or physician. The referral phase involves initial collection of demographic and medical information on the patient to make sure that they can safely receive and care for a transplanted kidney. The transplant center reviews patient insurance coverage for evaluation, surgery, and post-transplant care coverage as an initial step. Although all transplant centers must abide by the requirements of regulators, each has its own acceptance criteria. During the referral phase, baseline information is collected to assure that each patient meets the acceptance criteria. Briefly, this information would include: medical and surgical history; height, weight, and age; length of time on dialysis; and laboratory information including a serum creatinine and renal biopsy pathology results.

**Multidisciplinary Evaluation Appointment** Once initial referral criteria are met, patients (and family) meet with the interdisciplinary team for the evaluation appointment. The evaluation appointment has two major goals: assessment and education of the patient's health status and ability to safely receive a kidney transplant. During this

appointment, each patient (and family member, if they so choose) meets with a transplant-specific nephrologist, nurse coordinator, surgeon, social worker, and dietician.

**Follow-up Testing** The third, and often longest, phase is the follow-up testing phase. All patients will be required to complete all age-appropriate routine health and cancer screening tests such as mammogram, Pap smear, colonoscopy, routine blood work, TB screening, and dental health evaluation and/or treatments. Routine follow-up testing also includes cardiovascular evaluations, as well as additional blood work to evaluate immune function and virus exposure. Many CKD patients have multiple health issues in addition to renal failure. Each individual's unique health issues need to be reassessed, often by specialty consults, if they have not had recent, routine follow-up care. This often involves additional time and testing to complete the transplant evaluation. (See Appendix B)

### **Research Questions the Study Addresses**

Although many quantitative studies have explored various aspects of health disparities in renal failure and renal transplantation, there is an absence of research from the patient's perspective. This grounded theory study explores participants' actual beliefs and experiences in addressing the following important research questions:

What are the concerns of African American chronic kidney disease patients being evaluated for kidney transplantation?

How do these concerns account for their experiences during the transplant evaluation or affect their ability to complete the transplant evaluation?

## **Data Collection**

The above research questions led to the use of a qualitative, grounded theory design to collect and analyze the experiences of African American dialysis patients being evaluated for kidney transplantation. Data was collected for this grounded theory study through a demographic questionnaire, researcher observations, and two semi-structured interviews that were spaced about a month apart. The purpose of the demographic questionnaire (Appendix F) was to gather general demographic information on each participant. Additionally, the final two questions screened patients for the inclusion criteria for the study, ensuring that they had been referred for transplant evaluation and that they had not previously received a transplant.

The interview guide was used to focus the researcher and participants on the transplant evaluation experience, in order to explore their beliefs about health care and aspects of transplantation. The questions included in the semi-structured interview guide (Appendix J) were derived through the researcher's experience with the subject being studied, the review of the literature, and the objectives of the study. This questionnaire included probing, open-ended questions about the following topics: Participants' experience with interactions with the transplant center, including communications and responsiveness to their needs; beliefs about fairness and equality in terms of referral, organ allocation, and organ donation; how they managed the process of additional medical consults and testing; whether or not they equated transplantation with experimentation; and socio-cultural issues (family supports and faith-based beliefs) that are related to kidney transplantation.

One participant did not agree to have the interview audiotaped. During these interviews the researcher took notes to document this participant's relation of his experiences. Nine patients agreed to have their interviews audiotaped. These interviews were audiotaped using a small digital recorder that clearly picked up the participants' words, televisions, music, and conversations of other people in the unit, and the frequent alarming of the dialysis machines. Only the participants' words were transcribed and ambient noise was included in researcher memos only when appropriate.

Typically, four visits were made to each participant. On the first interview the researcher introduced herself and talked with the participant about the study. If the participant was interested and time allowed, the consent form was discussed. Several participants took the opportunity to take the consent form home and read it before agreeing to participate. The consent form was reviewed and signed before beginning the first interview, including the agreement to be audiotaped or contacted for future research studies. The first interview was conducted during the second visit. Prior to beginning the interview, the researcher addressed the confidentiality of the study, stressing that the information gathered would not be shared in any way with any of the dialysis or transplant care providers. The length of the first interviews ranged from 30 minutes to over an hour.

At the completion of the first interview the researcher set a date when the second interview would be scheduled. The first interview was transcribed prior to returning for the second interview so that the member checking would precede the second interview. This step helped to refocus the participants and give them feedback on the previous

discussion. Some of the participants read their own interview, and some asked the researcher to read it to them. Following the completion of the second interview, the data were transcribed, and the researcher returned to the participant for member checking again. Consistently, participants seemed pleased with the sound of their own stories and commented positively (or were neutral) about the accuracy of the transcription, how their stories were heard, and the developing themes. One participant expressed interest in reading “the end report” because he was interested in what others thought and the final conclusions of the study. Consistent with grounded theory methods, the researcher’s thoughts and observations regarding the interview experiences were collected in the form of memos.

Protection of the data was maintained throughout the process. The researcher collected, transcribed, and coded all of the interviews. Interview data is de-identified as stored and is contained only on password-protected computer hard drives (one primary and one back-up drive). All of the participant names have been changed to assure anonymity in reporting the study.

### **Data Analysis**

The simultaneous collection and analysis of the data, or constant comparative method, involved the researcher in the analysis throughout the process, including the transcription phase. All transcribed interviews were imported into NVIVO to assist in the organization and tracking of the coding process. Because this was the researcher’s first use of the software, much of the sorting and cross comparison of codes was done



manually rather than with NVIVO. The NVIVO software had the capability to hold and display the initial large number of codes, and allow the researcher to revisit the initial codes repeatedly to refine and merge them while the categories emerged.

Data were analyzed in grounded theory, using three phases of coding: initial coding, focused coding, and axial coding. The researcher used the Corbin and Strauss (1998) model of data analysis to search for theory within the data. The initial coding phase, however, involved line-by-line coding (Glaser & Strauss, 2001) to break the data down into its smallest components. Because the researcher is very close to the data, line-by-line coding was selected as the initial coding method so that preconceived notions would not be superimposed on the data. By using line-by-line coding of the interviews, the reduced data help the researcher begin the analysis with more analytic distance (Saldana, 2009).

Initial line-by-line coding resulted in approximately six hundred codes. These codes were compared for similarities and differences and merged into approximately 160 codes. These initial codes were provisional, and allowed the researcher to explore the data from different perspectives during the phases of analysis. Using the constant comparative methods of simultaneous data collection and analysis, other research questions were allowed to emerge and be explored. Following this the second phase of coding, focused coding was completed to group data into categories. The initial categories derived from focused coding included the following:

- Being me; my life and health
- Family and friends; support

- Anticipating transplantation
- Experiencing life on dialysis; relationships with dialysis staff
- Completing the transplant evaluation
- Having the financial support I need

In refining theory, Strauss and Corbin (1998) describe the process of “reviewing the scheme for internal consistency and for gaps in logic, filling in poorly developed categories, and validating the scheme” (p.156). At this point, the categories (and sub-categories) were related along their properties and dimensions and compared within and across all of the interviews to identify both similarities and differences. In the third phase of coding, axial coding, the categories, or phenomena, that developed during focused coding were linked conceptually to lead the researcher to the proposed theory, *Shifting Life’s Focus*, including the major concepts of financial concerns, complex health issues, and following through.

### **Trust, Trustworthiness, and Data Integrity**

Quality, trustworthiness, and safety of the data collected and analyzed during this study was a high priority from its inception. Beginning with the first contact with potential participants, trust must be assured. The researcher’s goal was to accurately represent the participants’ experiences, advocating for an alternative understanding in one aspect of health disparities in African American dialysis patients and kidney transplantation. Gaining their trust was essential to getting accurate stories, feelings, and experiences. In reality, it is likely that the level of trust between the participants and their dialysis unit, physicians, and staff would affect their ability to trust the researcher and the

research process and influence the depth of feelings and experiences they would share. The referral and consent procedures were developed to build trust with the participants. Willingness to speak with the researcher was ascertained by one of the lead staff members in each of the units before participants were referred. After receiving the referral the researcher would introduce herself and the study to a patient and discuss the study at length, sharing the consent information and the interview questions. In two cases, patients took this home and discussed it with family members before agreeing to participate.

Return meetings were scheduled with each participant at their convenience to allow them control over when they would be interviewed. Although many participants said “I’m here three days a week, come any time,” a few wanted to select the day that suited them best. This was especially common with the “first shift” dialysis participants who received their treatments in the early morning hours, spending most of their time on dialysis asleep. Allowing them control over scheduling their interview demonstrated respect, established trust, and assured that participants would be awake and interested in story-telling.

Frequent meetings with participants also helped foster trust and established trustworthiness in the study process. Spending sufficient time with the participants and performing two separate interviews helped to develop the relationship and supported the credibility of the research findings. In addition, each transcribed interview was reviewed with the participants and discussed. This step of “member checking” supported the credibility of the study.

Speziale and Carpenter (2007) defined the essential steps of demonstrating trustworthiness in qualitative research as credibility, dependability, confirmability, and transferability. Credibility, or “activities that increase the probability that credible findings will be produced” (p.48), was supported by developing trust with the participants, meeting with them over three, four, or five engagements, and member checking their stories and the ideas as they developed. In addition, the researcher had prolonged engagement with the subject matter having spent many years in the field of transplantation.

Dependability and confirmability of study results were approached throughout the steps of the process of coding by developing a clear, traceable audit trail able to be confirmed and retraced by others. In the process of coding this study, a second, very experienced researcher (medical anthropologist), validated the coding of the initial interviews (line-by-line coding). In addition, two experienced transplant nurses reviewed the concepts and theoretical framework to validate the findings of the researcher.

Transferability, or the probability that the study findings have meaning to others in similar situations (Speziale & Carpenter, 2007, p.49), should be assumed by the coherence between the study population and similar findings in the literature review and will be validated in future studies.

Through every phase of the study process, the data were protected by the researcher, de-identified and located in password-protected computer files accessible only by the researcher. Taped interviews were destroyed. The stories live on, though, in the grounded theory, *Shifting Life's Focus*.

#### 4. FINDINGS

The findings of the study performed to understand the concerns of African American chronic kidney disease patients being evaluated for kidney transplantation are presented in this chapter. In exploring their concerns and beliefs, a theoretical framework emerged that explains how patient experiences affect their ability to complete their kidney transplant evaluation. This theoretical framework, *Shifting Life's Focus*, will first be described; an explanation of the three major themes and subcategories follows.

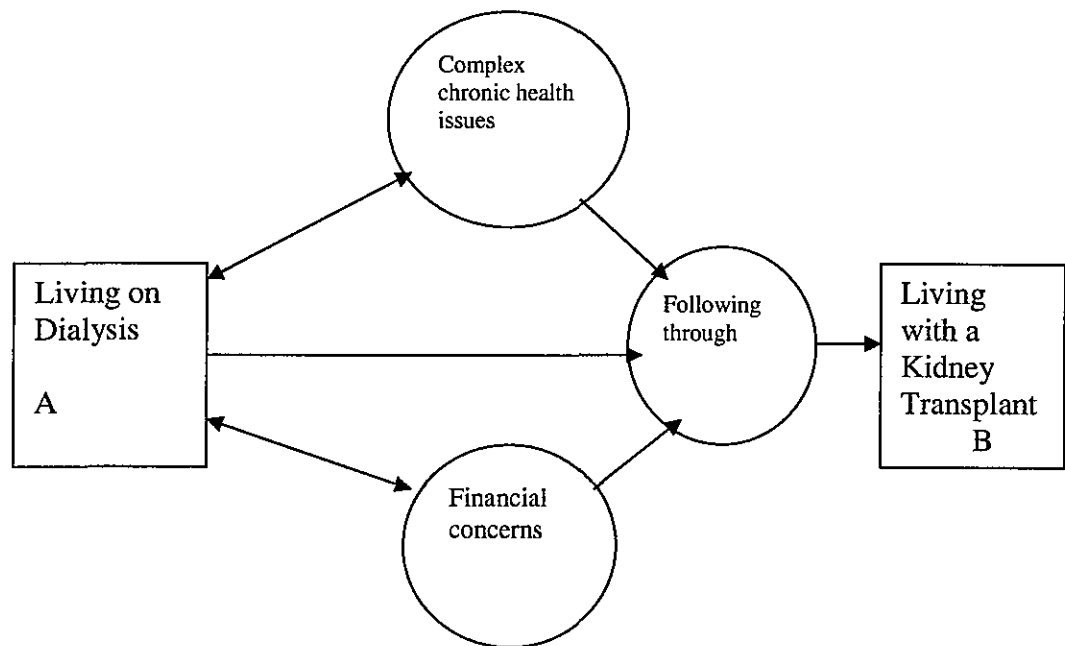
*Shifting Life's Focus* represents the theoretical framework of participants' experiences with transplant evaluation, because this label indicates that they are working through a significant potential life change and refocusing. Transplant evaluation involves shifting life's focus, but not just the obvious aspects of working through a transplant clinical evaluation and looking forward to getting a new kidney so that they can terminate dialysis. Each individual had more than two years' experience with chronic dialysis and had begun to rearrange and organize their lives and their living around the consistent demands of a three-times-a-week treatment schedule. They had learned all of the medications that go along with chronic dialysis maintenance and described how they had planned to fit them into their activities and meals. Perhaps the hardest change of all to incorporate into their lives was the dietary restrictions accompanying chronic dialysis. In addition, all had stopped or at least altered the frequency of their employment and,

accordingly, their means of income for themselves and their family. In essence, these participants and their families had adjusted to their chronic disease through many lifestyle changes and restrictions and had revolved a part of their lives around the dialysis unit, dialysis unit staff, and other medical providers. Although chronically ill and dependent on dialysis, these participants had gained some level of life balance.

The theoretical framework *Shifting Life's Focus* that emerged from the study data includes three major themes and seven sub-categories (Table 2). Together the themes and their categories comprise the proposed theory (Figure 1).

**Table 2. Themes and Categories**

Themes	Categories
Financial Concerns	<ul style="list-style-type: none"> <li>• Concerns about income and work</li> <li>• Experiences with insurance and beliefs about insurance</li> <li>• Affording to live and pay for medications after receiving a transplant</li> </ul>
Complex Chronic Health Issues	<ul style="list-style-type: none"> <li>• Chronic disease</li> <li>• Changes in activity and relationships</li> </ul>
Following Through	<ul style="list-style-type: none"> <li>• Experiences with the transplant evaluation</li> <li>• Anticipating getting a kidney</li> </ul>



**Figure 1. *Shifting Life's Focus***

The model (Figure 1) demonstrates the transformation line that moves from being a dialysis patient on the left to being a transplant recipient on the right. The concepts of financial concerns and complex chronic health issues impact the experiences at points A and B and continually along the transformation line. Also, these concepts (financial concerns and complex chronic health issues) impact the experience of living on dialysis, as seen by the two-way relationship arrows. As the transformation approaches point B the third concept, following through, must be encountered to get to point B. Following through is also influenced by the concepts of financial concerns and complex chronic health issues. The core concept, following through, is impacted by all other concepts and connects the transformation line from living on dialysis (point A) to living with a kidney transplant (point B). Together, these concepts interact with the transformation line to become the framework of the theory *Shifting Life's Focus*.

### **Kidney Transplant Evaluation**

The option of kidney transplantation was mentioned to each of these participants by someone in the dialysis unit, their doctor, or perhaps a family member or friend. Each of them knew or knew of someone who had received a kidney transplant; sometimes it was a friend or a relative and sometimes that person was a former dialysis unit patient. At some point, each of these participants made the decision to be evaluated for a kidney transplant and had begun the process.

The transplant evaluation process involves three phases; referral, evaluation appointment, and medical work-up phase. The length of time each patient experiences a phase depends on how quickly the patient is able to finish the standard testing as well as



which testing might be specific to their individual health concerns. The testing is requested by the clinical team at the involved transplant center, but the patient is responsible for managing their way through the many appointments and tests that are required. (See Appendix B for the list of required testing.) A patient cannot be put on the list to receive a donor kidney until all testing has been completed and they have been approved as a recipient by the transplant center. The opportunity to receive a transplant means not only completing a lengthy variety of medical tests and consults, but reorganizing their balanced lives in different ways, and changing their role of dialysis patient to a new role.

### **Financial Concerns**

“If you have money you can have all the health care you want.” -David

Participants discussed their financial concerns as they related to everyday life, being on dialysis, going through the transplant evaluation, and anticipating post transplant-related care costs. As described in the demographic summary, all of the participants stated that they had Medicare as their insurance provider, and only one of the participants had private insurance in addition to Medicare. Information specific to Medicare coverage (and patient costs) related to dialysis and kidney transplantation is summarized in Appendix C.

**Concerns about Income and Work** Only one participant was currently working while on dialysis, part time. The rest had either not worked, retired, or stopped working due to the combination of the demands of their dialysis treatment and fatigue related to their renal failure. One participant, Sam, the youngest of the group in this study, was actively

looking for part time work while on dialysis. Larry and Shirley anticipated working after transplant as a reason to get a transplant, indicating that they wanted to work again. Tom acknowledged that getting a transplant meant that he would have to go back to work. “It [getting a transplant] would mean I would have to go back to work...because assistance would stop. It doesn’t make any sense to me. We just barely scratching out a meager living but we are living.”

**Experiences with Insurance and Beliefs about Insurance** David, who was retired, received private health insurance (in addition to Medicare) from his former employer. He found dealing with his insurance company extremely difficult while others (without private health insurance) focused more on anticipation of the changes in coverage after transplant.

Now (getting to appointments) it is up to me and I am supposed to go through my primary doctor (required by his insurance company). My doctor charges me \$35.00 every time she sees me....I also now have to pay an additional \$200.00 a month because this doctor comes around and sees me (in the dialysis unit) once a month. Before I only saw the doctor about once a year. I can barely pay my income tax less yet \$200.00 (a month) more. -David

Beckett, who did not have private health insurance, believed that having insurance was the key to good health care, and perhaps the key to getting on the transplant list or getting a kidney.

I don’t think (getting on the transplant list) is a black-white-Oriental thing. I think it’s about the ability you have to get certain insurances. And what I have

learned is that anybody who has insurance, personal insurance and they pay it, I think they will get a kidney quicker than a person that's on disability or Medicare and Medicaid. -Beckett

In general, participants in this study experienced regular concern about paying for daily living expenses. The financial cost of their illness was an added burden. Although Medicare pays for transplant evaluation testing, additional costs existed in completing the transplant evaluation that were difficult to manage. For example, while having a mouth free of infection prior to transplant is an important part of the preparation for getting a transplant, this part of the evaluation is not covered by Medicare. Sam had to have dental work completed and was unable to cover the cost, even though it was the only thing preventing him from completing his transplant evaluation.

You know, it's like I had went to the dentist and had to have some dental work done. So KDP was paying for some of it, and there were certain processes that they weren't covering. So at my first visit it was like a hundred and some dollars. But for me, I am living from government check to government check and I don't have money to put off to the side, you know... I was there at the dentist and they wouldn't do it (dental repair work) without the money, and I didn't have the money. Like right now, I don't have the money to get it done. - Sam

Another expense related to completing the evaluation testing that had to come out of the patients' pockets was money for transportation. In the words of David, "It costs me money every time I have to go somewhere to do more testing."

Many also did not feel that there were others—family or close friends—that they could turn to for financial support. The majority of participants had selected the lowest category (< \$25,000 per year) for their combined family income on the demographic form, and just did not have the resources needed.

I got this girlfriend but she is struggling too, you know. She is a single parent so she is struggling and I am struggling and I really don't have people that I can just call up when I have a need like that. -Sam

A lot of people just don't get the care because they are worried about putting food on the table. -Sam

The added cost of transplant evaluation as well as testing generated enough concern that the discussion about staying on dialysis as compared to getting a transplant revolved around affordability, rather than the treatment that was desired. When the cost of transplant was evaluated, dialysis did not look as unpleasant. Consider Tom's statement: "And the other factor of mine is finances. The way finances are today, I'm not bad being on dialysis and it's not killing me."

#### **Affording to Live and Pay for Medications after Receiving a Transplant** A

significant part of the transplant evaluation involves education about the costs after transplantation. Costly immunosuppressive medications need to be taken for life; however, unless the patient is on disability at the time of kidney transplantation, Medicare coverage for these medications stops at three years after the transplant for those who have not reached Medicare eligibility due to their age. Many patients seemed to understand that they would need to work after receiving a transplant to pay for

medication coverage to keep the kidney. Those without a work history that would assure adequate employment expressed anxiety about being able to get the right kind of job that would give them adequate benefits to pay for their transplant.

What am I going to do? What is the use of my going and getting this transplant knowing that I have to take this medicine in order for the transplant to be successful? I know that where I am at right now I probably wouldn't afford the medication. Why take the chance and not be able to get the medication and the kidney failed and somebody else could have got it and been able to do what they needed to do when they get it, you know... that's just life.

-Sam

Because after I weighed the pros and cons, it [getting a transplant] wouldn't be feasible. I don't think that after the transplant I would have been able to go back to the workforce and provide for my family. -Tom

A majority of the male study participants expressed financial concerns; however, few of the female participants discussed this issue. As a group, the women were older and perhaps closer to Medicare age than the males. Although marital status was not requested, female participants talked about husbands and other supportive family members with whom they lived (sons or daughters). One reason for not addressing a financial concern may be that these women received some financial support from these relationships.

## **Complex Chronic Health Issues**

**Chronic Diseases** CKD (and dialysis) is only one of the many chronic conditions that participants experience. Living with a combination of chronic dialysis as well as other health conditions affected these patients' lives during both dialysis and their daily living while not on dialysis. The complexity of their level of illness often prevented them from being able to get finished with their transplant evaluation and compromised their control over their lives. Because these patients had been on dialysis for such a long time (averaging more than 7 years), many had adjusted to dialysis treatment and "accepted" it.

So I tell people 'dialysis is not a death sentence, it's a change of life. You should accept that things happen for the best.' I know what medicines I get; I put my own bandages on, my own tape on...That's why I say the biggest attribute to myself is acceptance. -Tom

All of the participants described their health needs and some discussed how these concerns were preventing them from getting through the transplant evaluation. A majority of these chronic diseases may have contributed to their kidney failure but would not be corrected by receiving a kidney transplant. Several patients experienced diabetes and hypertension, the most frequent causes of kidney failure in this country. Other chronic diseases affecting these patients included HIV, sarcoidosis, hematological disorders, coronary disease, sleep apnea, anxiety and depression, and obesity. Obesity has been a roadblock in the road to dialysis for several of these patients, who have been told that they must lose weight, in addition to completing all of the testing for transplant evaluation, to be put on the transplant list.

But I still can't get over it...because when they called and told me about taking me off the activation list because of two pounds.....That is the main thing that I have to work on...getting the weight off. But since then I done gained about five pounds, but now I'm about seven pounds up. -Beckett

In fact, Pam's dialysis physician stated that she (Pam) had received a letter removing her from the evaluation process due to her inability to lose a requested fifty pounds. Pam continued to tell me she had to lose fifty pounds to get a transplant, but did not tell me about receiving the letter of removal from evaluation. Patients who are obese when they begin dialysis find it difficult to take off any weight while on dialysis due to dietary restrictions and lack of exercise. Although every dialysis unit is staffed with a dietician, the dietician's role is to teach and evaluate patient's compliance with their renal diet, not weight loss.

**Changes in Activity and Relationships** Dialysis patients experience changes in their activity and relationships due to the confines of treatment and fatigue of renal failure. They experience weakness, boredom, being tired of being sick, dietary and other restrictions. Their life and health revolves around their dialysis schedule and dependency on their care providers. Many patients discussed their relationship with the clinical team members in the dialysis units.

I joke with the techs when they start [referring to new dialysis technicians]. I say "y'all should have to sit in this chair for four hours. That should be the first training you got." A lot of them say 'why do you want to go to sleep?'

And I say “that’s why you need to experience sitting in this chair for four and a half hours.” -Beckett

The technicians who run the dialysis machines are always present in the units. Some participants expressed animosity toward them as well as toward other patients in the unit and unit administration.

We are human beings. If half of these techs had an individual in this condition they would not treat us the way that they do. If they had somebody on dialysis they would understand our emotional state. They wouldn’t be like, well, I’ll get to you when I get to you. How can you empathize? How can you feel something if you never know? They are assuming. You can’t assume on our lives... These are our lives you are screwing with. I am not a game. -Tom

I can only speak for here (this unit). This management changed. The manager that came in- she says one thing and does another. She’s all mouth. No action whatsoever, just mouth. -Tom

Throughout the interviews a distinct difference was noted in the relationships between patients and staff at the three different units. The social worker at one unit was lovingly referred to by participants as being supportive and helpful to them. She was the person who initially suggested transplant and listened to their concerns. The participants in this unit had a vastly different relationship with the social worker than the staff or administration. In another unit the staff were not mentioned at all by the participants,



except indirectly in saying that they did not know who to ask about their transplant evaluation nor did they know what testing they needed to complete to get finished with the evaluation.

In contrast, patients from one unit all talked about the assistance and support provided by certain dialysis unit staff, and creatively suggested things that they wanted to discuss about care in the unit as though they were a valued part of the team. Speaking of one of the staff, Larry said, "Lisa made sure. She kept reminding me every time I came here. She knew I had a habit of forgetting appointments."

One thing that I think is that we as patients should have some kind of meeting of the minds of patients every month with someone who can put things into effect. There should be a meeting where patients and staff can sit down together in a meeting. I am going to suggest that to the Medical Director. -

Beckett

In this particular unit two of the participants referred to the dialysis staff as "like family to me", and said that they would miss them should they receive a transplant and not need to come to dialysis anymore.

Relationships with family and friends also changed due to the chronic needs of dialysis. Many found themselves withdrawing from activities due to fatigue and treatment issues.

They (family members) don't understand what you go through. It's really like, you're talking and they don't understand and they can't get through the conversation with you. A lot of people say that they think I'm depressed but

I'm not depressed. I am just physically weak. They can't understand it because they [are] used to seeing me [as a] football player and in school playing basketball, and every time there is a cookout or a function or a wedding I'm there....no it's like every time I ain't there some people might say I'm depressed or mad at somebody. They don't understand I'm just tired. Until you walk in my shoes don't try to tell me. Until you have been on this machine and you can feel the ramifications of being on it, how weak you feel, you get sick. As soon as you get better from that something else comes up. And so, they just don't understand that. And I understand why they don't understand that because they never went through it. I don't get upset with them or nothing. -Beckett

You really can't do things that you want to do and you get tired. Sometimes I get tied real fast. -Shirley

I feel so weak from the time that I leave here until I get ready to come back in here. The family, they call me up about cook outs and parties and I never what to go. -Beckett

### **Following Through**

**Experiences with Transplant Evaluation** Most participants, with the exception of Pam, pursued transplant as a treatment option following discussion with one of the dialysis unit

staff (Pam stated she “can’t remember but thinks it is a doctor”). The referring staff person was different in each of the three dialysis units: a social worker, one of the nurses, or the nurse practitioner who oversaw daily dialysis care and orders. One patient referred herself directly to the transplant center for her evaluation.

Pursuing transplant as an alternative treatment may have been initiated by someone other than the patient, but the decision to move forward was clearly the patient’s alone. Only about half of the participants described that a family member was strongly supportive of their decision to move forward with transplant. The majority stated clearly “it was my decision” to get a transplant (or in a couple of cases, not to get a transplant), as demonstrated by Evelyn’s description: “Well, we all talk about it but basically they let me make, you know, my own decision. So if I feel that I’m able to do something, or whatever, they go along with my decision.”

Initially, following referral for transplantation, adult children of several patients expressed support as well as willingness and enthusiasm to be tested as a potential living donor. However, when related donors were not available, enthusiasm and support for helping the parent complete the transplant evaluation declined and life on dialysis continued. Only one of the participants in this study, Jennifer, had a viable living donor who had completed evaluation and been accepted as a living donor.

Oh, my daughter [was involved in my decision to be evaluated]. I talked to them about it. Most the family has kidney problems. So when I asked them about donating, then they had problems too. -Jennifer

Two of my daughters, they suffer from high blood pressure, and my grandson- I really didn't want him to get involved because I thought he was too young and at that time he was into basketball and stuff. So he still wanted to get tested. But when he got tested he had high blood pressure. -Sarah

Although participants recalled initiating the evaluation process more than a year prior to the interview (in some cases, two or more years), only one person had completed the evaluation and all of the workup testing, met the criteria for acceptance, and was placed on the waiting list. Several participants were unsure of what steps remained to be completed to be placed on the list.

Four of the ten participants had to restart the evaluation process after failing to complete it the first time. Their lack of follow-through with testing led to being removed from the evaluation process by the transplant center.

When I first started I had a whole lot of different things going on and, I had a lot of different health issues. And every time I got started something else would come up and I had to just start over again. Every time I would get almost done I'd have to start over again. -Larry

Completing the workup following the evaluation appointment was difficult for many patients. In one particular dialysis unit, patients were unsure of what testing needed to be done and whom to call to find out. They knew that they had a transplant coordinator but did not remember the coordinator's name or know where to find the phone number. Interestingly, these patients indicated they had not asked dialysis staff for

help, but still wanted a kidney transplant. “Yeah, I still want it [a transplant]. I hope they don’t get me eliminated [because I don’t have my testing done].” -David

Patients had difficulty remembering appointments (for evaluation testing requirements) and going to appointments.

...but as far as completing the evaluation, as far as myself goes, I was getting tired of all of the appointments. I was getting tired of it and I was thinking of saying “the heck with it”. I want to live a little longer, so I just stuck with it. Even though I was going through all of the health issues and I had to start all over again, I just stuck with it. -Larry

One dialysis unit accepted the responsibility for much of the scheduling on behalf of patients, as well as reminding patients ahead of the appointments. Not surprisingly, this was the unit where dialysis staff were referred to by patients as “like family to me”.

Everything is OK. Now usually if I have a problem or something I talk to Lisa and Lisa hops right on it. Say like I wanted to call the transplant coordinator I would tell her and she would call and tell the transplant coordinator I want to talk to her and give her the number. They are great here. -Jennifer

**Anticipating Getting a Kidney** All of the study participants had thought about getting a kidney and living life off of dialysis, but it was not the idea of freedom from dialysis that pushed them to complete the evaluation. In reality, they seemed to be very slowly moving through the steps of the evaluation and work up. Two patients, Pam and Beckett, had obesity standing in the way of getting on the list and both seemed to feel pretty

hopeless about changing that condition. Indeed, Pam had been removed from the evaluation process by the transplant center, and Beckett had actually gained weight.

Although they had not informed the transplant center, Sam and Tom openly admitted that they did not want a transplant, as discussed previously under the “financial concerns” topic. Both patients believed that they could not afford the added cost of a transplant because of their unwillingness or uncertainty to gain employment that would provide adequate benefits after Medicare coverage for immunosuppression medications ended. Tom, who had kidney failure from HIV disease, also said, “It’s not that I am not deserving of one [a kidney], but there are other people who get it [kidney failure] naturally and I always had the impression that they should get it [kidney] first.”

Sarah, who had completed the evaluation and was placed on the waiting list, said that she was not expecting to get a kidney soon: “Because I know it’s so hard to get a transplant; if I get one I’ll deal with it then. I’m not thinking it’ll be next year or next week or anything like that.” While attached to both an oxygen tank and dialysis machine, Sarah spoke of her reluctance to take a kidney that someone else could receive.

I don’t know how to put it into words...not just children. I think if I sees somebody who looks sicker than me, I would want them to have it (the kidney transplant) faster than me no matter what. You know. So that’s why I really don’t think about it. -Sarah

Dialysis had become something to which the patients had adjusted, and anticipating transplant meant that there would be many changes they would need to incorporate into their lives. These changes, in many ways, revolved around needs of their loved ones and

thinking of others as reflected in the comments by Tom and Sarah above. Other changes they were anticipating were financial, and changes in their overall health care management, and changes in their current relationship with dialysis staff, family and friends. .

Many, but not all of the participants, felt that they had the support of family and friends to care for them after transplant. Shirley, who lived with one of her daughters, did not:

I really don't have no one to be there with me and I don't have nobody to help take my medicine. My son is looking for work and sometimes he just leave out. And I probably could stay with my daughter but I don't really want to be a burden to nobody. -Shirley

Experiencing chronic dialysis requires many life adaptations for kidney failure patients. Each participant in this study decided to pursue transplant evaluation, and each decided to participate in this study about their experiences with transplant evaluation. The concepts that were extracted from the analysis of their stories have been described in the proposed theory *Shifting Life's Focus*. If a participant wants to become a transplant recipient they must complete their transplant evaluation and prepare themselves to shift the focus of their life from being dialysis-centered to something else. The role of dialysis patient will change to the role of transplant recipient.

This is a proposed theory based on findings to date. It is the researcher's expectation that the theory, or the concepts, may change with additional interviews conducted in additional future studies.

## 5. DISCUSSION

### Findings

*Shifting Life's Focus*, the substantive theory that emerged from this study, explains the participants' experiences with the process of kidney transplant evaluation and the prospect of becoming a kidney transplant recipient. This detailed and demanding process involved acting (pursuing additional medical consultations and testing) and learning (about changes that would be required in their lives off of dialysis). Essentially, should they complete the actions (transplant evaluation), the participants would eventually be required to make a choice—remain on dialysis or become a transplant recipient. Because these participants had adjusted to a life of chronic dialysis, the experience of transplant evaluation required each to *shift* the focus of their lives from dialysis to transplantation.

Three major concepts that are included in the theory *Shifting Life's Focus* are financial concerns, complex chronic health issues, and following through. Together these explain the theoretical framework. A selective sampling of the literature was undertaken to understand the current published works related to the concepts that developed from this study. The literature and discussion will be presented under subheadings of each major concept.



## **Literature**

The body of research related to health disparities, particularly concerning African American kidney failure patients and kidney transplantation, continues to grow and develop, fueled by the incidence and associated cost of ESRD. As care and treatment for all patients with kidney disease expands to consume a larger and larger percentage of overall health costs, the research focus has broadened. The evidence in this study tells one story, from the perspective of ten patients, about how they experience the process of transplant evaluation.

**Financial Concerns** Expressions of financial concern by participants in this study were frequently linked to concerns about employment. Only one patient was employed. Others expressed concerns about obtaining the kind of job that had “good benefits”. Most had not completed high school and therefore had limited employment options. This inability to find appropriate employment precluded access to private medical benefits, and some patients expressed concerns about having to move from the government support they received while on dialysis (Medicare and disability payments) to being self-sustaining after transplant. That Medicare insurance would cease 3 years after a transplant led to anxiety about “what then?” The stability of Medicare coverage for their health care while on dialysis was comfortable; losing that coverage was a serious concern.

Similar financial concerns are reported extensively throughout the literature. Norris and Agodoa (2005) studied racial disparities associated with kidney disease, and found

that that the proportion of non-elderly African Americans considered to be below the poverty level was 31%, and that 45% of African Americans were uninsured or received publicly funded health care. They concluded that reduced SES negatively influences access to health care, as well as access to kidney transplants. In their study about social environmental stressors and kidney disease, Bruce et al. (2009) lament the lack of changes in the economy for forty years following the civil rights movement and note that African Americans are still residentially segregated with substandard educational resources. In studying barriers to renal transplantation, Alexander and Sehgal (1998) analyzed the ability of patients to complete the phases of transplant evaluation. They found that although African Americans were interested in transplants and started the evaluation process, they were less likely than whites to move through the phases of transplant evaluation, and that patients from zip codes with lower income levels were also less likely to complete the transplant evaluation.

Because of the complexity of biomedical and psychosocial factors that are believed to cause CKD, poverty has been identified as a risk factor for this disease (Young, 2010). The financial concerns that participants expressed had to do with everyday living, completing the transplant evaluation, and deciding whether they could afford to receive a transplant and live with the transplanted kidney. Because of the years of dialysis, they had become very aware of the cost and benefit of that treatment method. Additionally, they had not gained additional education or work skills while on dialysis; indeed, the opposite was true. Therefore, their concerns about changing treatment from dialysis to something that seemed likely to be more expensive (transplantation) were very realistic.

These financial concerns may partially explain why, in many studies, African American patients are interested in kidney transplant and start the evaluation process, but their interest subsides when more information is acquired during the evaluation process. As they consider the cost amid other lifestyle changes, their enthusiasm wanes. In the study by Alexander and Sehgal (1998), the process of transplant evaluation was divided into phases. The findings (that poorer and African American patients are less likely to complete the evaluation) may be partially due to this same education and reasoning process.

**Complex Chronic Health Conditions** Chronic health conditions in addition to the kidney failure directly and indirectly affected by every participant in this study. Each person coped differently with their health issues; for some these issues added complexity to their dialysis regimen, for others they meant more difficulty in finishing the transplant evaluation. However, for two patients with significant obesity, this health issue meant exclusion as a candidate for kidney transplant if significant amounts of weight were not lost. As the literature expands regarding the growing problem of chronic renal failure and its associated causes and consequences, more is known about the burden of co-morbid conditions in the population including obesity, diabetes, and hypertension. An example includes the study of Buckalew and Freedman (2010) on the impact of race on survival in patients on dialysis, which addressed the problems of obesity, dialysis, and hypertension. Further, they stated that kidney failure from HIV infection “nearly always occurs in African Americans” (p.1104). The Jackson Heart Study (Bruce et al., 2010)

also identified the extent of complex chronic disease burden in African Americans with CKD in over 5,000 African American adults.

Obesity represented a particular barrier for two of the participants in this study. They were told by the transplant center that significant weight loss was required prior to approval for transplant. Although neither had enrolled in any kind of weight loss program or tried to keep track of their dietary intake, they believed that weight loss was difficult, if not impossible, for them while on dialysis and were angry that they might be excluded from getting a transplant. A great deal of attention has been paid to the rising incidence of obesity in the general population, and specifically as it relates to renal function, renal failure, and kidney transplantation (Bombeck, 2010; Hossain, 2009; Lynch, 2009; Toto, 2010). Indeed, Bombeck reported that obesity and metabolic syndrome are more pronounced in African Americans, who have higher rates of CKD and ERSD than Caucasians.

Although obesity is directly related to kidney failure, the condition also directly affects a person's ability to receive a transplant for surgical reasons. Two studies (Segev, 2008; Lynch et al., 2009) indicated that severely obese patients who receive renal transplants are at a higher risk for developing surgical site infections following kidney transplants, and that these patients are passed over when organs are allocated to transplant centers.

Living with chronic medical conditions and dialysis requires a daily focus on health management for all of these participants. Each explained how they accommodated their illness and dialysis in their lives, and what getting a transplant meant to them. For most it

meant a trade-off of one type of chronic illness maintenance (dialysis) to another (following a transplant). These participants knew that the underlying problems (diabetes, sarcoidosis, HIV) and the care and treatments of these problems would continue to require management following transplantation. They had adjusted to dialysis along with their illness; anticipating moving from dialysis to transplant was a part of their decision-making process.

### **Following Through**

**Experiences with transplant evaluation.** Moving from chronic dialysis to being a transplant recipient involves completing all of the required testing (within a certain time frame) and receiving a donor kidney. Experiences with the transplant evaluation varied according to the dialysis unit where the patient received treatment, the amount of guidance and support they received, and their general understanding of and engagement in the process. Getting through the evaluation required understanding, organization, transportation, ability to communicate with the transplant center, and the time and ability to withstand many consults and tests. Weng et al. (2005), believing that the transplant evaluation itself might be a barrier to transplantation for African American patients, studied rates of completion of the medical evaluation for renal transplantation. Results of Weng's study indicated that African American race is associated independently with slower completion of the evaluation, and that social networks and relationships help patients complete the transplant process. In this study, the relationships supporting the completion of the transplant evaluation testing were primarily the dialysis unit staff

members' activities related to scheduling, reminding patients about appointments, and providing encouragement for them.

Another study investigated educational level as a determinant of access to kidney transplantation. Schaeffner (2008) found that the highest educational level was associated with a 3-fold greater rate of being wait-listed for transplant than patients in the lowest educational category. Importantly, social support and SES are two concepts that relate directly to the experiences of this study population. In this study, many relied upon dialysis unit staff as their only support network to accomplish the completion of the medical testing requirements for transplantation. In addition, the demographic of the participant group was that of unemployed, lower income, and lower educational level. This study supports the findings of Shaeffner's previous study in outlining the difficulty the participants had in completing their transplant evaluation.

The majority of participants began their transplant evaluation at the suggestion of staff in the dialysis center. Appropriately, the dialysis center should be teaching their patients about the options for care, and particularly the opportunity of kidney transplantation. In some of the dialysis centers in this study, the support extended to scheduling and reminders about appointments. These centers were invested in assuring that their patients had the opportunities that all patients should have for transplantation. The participants, however, were making their own choices once they understood the risks and benefits to them, and once they had experienced the amount of change that would be involved. In one center, the participants felt that the dialysis staff were "like family". The close relationships that developed within the culture of the dialysis unit and with the

regular support of caring staff were important to these participants and had become an important part of their social support systems.

Choosing to receive a transplant meant that they would have to leave this important support system behind, perhaps *Shifting life's focus* to an unknown or perceived absence of the same level of support for their health care needs. *Shifting life's focus* also means, in this example, trusting that the support resources will be there in the revised area of health care (transplantation care). In the studies by Powe and Melmed (2005), and Cort (2004) lack trust in clinical providers is high in African Americans. This further supports the reluctance to shift care from trusted, supported providers (in dialysis) to the unknown, untrusted group (transplant providers).

Many studies have investigated the influence of social support on chronic illness self-management, especially in the area of diabetes. In Gallant's 2003 review of the literature examining this topic, several focused on CKD. Gallant states that "future interdisciplinary work that better links the self-management and social support literatures would be ideal"(p.188). This linking literature has begun to appear in the ESRD/dialysis/transplantation field to help identify the racial disparities present.

**Anticipating getting a transplant.** Study participants who had completed their transplant evaluation openly expressed feelings of conflict in becoming transplant recipients. Although very sick herself, Sarah said that she thought that she would feel better if a kidney would go to someone sicker than she was. Tom, who was HIV-positive, believed that a kidney should go to someone who got their kidney failure "naturally" rather than him. Both were expressing concern for others and not themselves.

These beliefs were very telling of some of the mixed feelings the patients experience. As these participants anticipated the shift in their lives' focus from living on dialysis to living with a kidney transplant, they understood the impact of this change on the important relationships in their daily lives.

Choices were also affected by the perceived financial impact of getting a transplant. The majority of participants experienced financial concerns about being able to afford the medications and lifestyle of a transplant recipient. As described in the literature, and reinforced in the demographic summary of this population, financial issues were real since income levels were low and the possibility of finding work with "good pay and good benefits" was remote.

### **Limitations and Strengths of the Study**

The limitations of this study include the small sample of long-term dialysis patients. Results may reflect the experiences of long-term dialysis patients but would be less likely to reflect experiences of other African American CKD patients who need a kidney transplant. Because of educational efforts to identify kidney failure earlier in these high risk populations, it is hoped that the choice of transplantation will come earlier for most patients. Although all patients were being evaluated at one transplant center, and results may reflect the experience of that center only, the study was located at three different dialysis centers.

Study strengths include the methodology. Little is published addressing the actual experiences of long-term dialysis patients who pursue kidney transplantation. The growth in CKD and continuation of the disparities between African Americans and



Caucasians who are listed for and receive kidney transplants require comprehensive methods to research these problems. Throughout the process the concern for analytical integrity and trustworthiness was maintained through member checks, verification, and ensured credibility. First, member checks were carried out with the participants to assure clarity in understanding their experiences as described. Prolonged engagement in the field through multiple visits to carry out consent, two interviews, and member checking helped to build rapport with the participants and staff in the units. Second, initial (line-by-line) coding was validated on two interviews with a second researcher (medical anthropologist). Third, to ensure dependability and credibility the final concepts and the conceptual framework were reviewed and verified from a clinical perspective by several experienced transplant nurses.

In addition to demonstrating credibility, dependability, and confirmability through the activities described above, this study also demonstrates transferability. Based on the coherence between finding with the study population and that of the literature review, the theory *Shifting Life's Focus* will have meaning to other situations.

Development of a theoretical framework for understanding the experiences of completing a kidney transplant evaluation can assist clinicians in fields of both dialysis and transplantation and should also influence public policy development. As CKD and its treatment continue to consume larger and larger proportions of the Medicare budget, this framework should assist in balancing between cost and outcomes.

## **Recommendations/Contributions to Policy and Practice**

The theory developed from this study has direct and immediate implications for both clinical practice and policy. Because of the large amount of public funding (primarily through Medicare) that supports ESRD and transplantation in the U.S., both dialysis and transplantation are heavily-regulated clinical fields. Policy and outcome measures drive practice in many centers, to maintain consistency, equity, and transparency for referring providers and recipients of care.

### **Policy**

**Reduce unnecessary repeat testing and reevaluation of potential recipients through a phased-in evaluation process that is more standard and consistent across all transplant centers.** Because of the ambivalence and inability of some patients to complete their transplant evaluation in a timely manner, testing is frequently repeated. Repeated testing costs Medicare (or any other payer) money that could be spent more effectively. Standardizing phases of evaluation and moving forward with a phased-in approach while providing education and decision-making support may prevent such waste. A model of phased evaluation testing with the dual goals of reducing waste and individualizing the process could be piloted through the regional renal networks.

**Mandate routine health screening tests for dialysis patients on Medicare and Medicaid.** Because a majority of dialysis patients do not pursue routine health maintenance screening (mammograms, pap smears, colonoscopies) patients come to transplant evaluation without routine health screening. These tests then have to be completed along with the transplant-specific evaluation consults and exams, which adds

to the testing burden and the overall cost of the transplant evaluation. Not uncommonly, a patient will complete the majority of their testing except the colonoscopy, and take months or even longer to complete this test.

**Expand funding for dental care for those who cannot afford it.** Dental care is not covered by Medicare and many people cannot afford routine dental visits. Patients may be able to complete the remainder of their evaluation but the cost of dental care precludes that important step. Although each state has limited funding for indigent dental care, the funds and the dentists who will care for these patients do not meet the needs. Additional funding for dental services for moderate and low income dialysis and transplant patients needs to be provided.

**Support Vocational Rehabilitation.** Increasing numbers of dialysis patients stop working due to the demands of treatment and find it hard or impossible to return to work following a transplant. This restriction is especially significant for those with limited skills and educational preparation. Dialysis and transplant planning should incorporate a comprehensive rehabilitation model that includes vocational rehabilitation.

**Extend the option for Medicare coverage of immunosuppression following transplantation.** The concern of losing Medicare coverage for the expensive immune-suppressing drugs that are required for life following transplantation has implications beyond this study population, but is particularly important for poorer, undereducated and underemployed patients of all races across this country.

## **Practice**

**Partner with the transplant liaison in each dialysis center to understand each patient's potential transition from dialysis to transplant.** The transplant liaison is a relatively new role in the dialysis unit that has been mandated by the Maryland Kidney Commission to assist in the identification and referral of patients for transplant evaluation and to liaison with the transplant centers. The theory *Shifting Life's Focus* can serve as a framework to assess and guide the dialysis patient as they learn about transplantation and proceed through their evaluation. The concepts and theoretical framework may better support the liaison in providing each patient with the choices they need to make throughout the process.

**Refocus the transplant evaluation and testing process.** Tailoring the transplant evaluation process to better meet the needs of individual patients may improve how the evaluation is completed, the ability of the patient to fully participate, and the reduction of wasted testing. This process will need to occur in collaboration between the dialysis centers and transplant centers and should include added education and support. Important aspects to include in assessment and education before, during and after the referral for transplant evaluation include:

1. Assess each patient's health decision-making before initiating the evaluation.
2. Describe what transplantation means in terms of shifting the patient's life focus.
3. Revise education and referral practices with dialysis units and referring nephrologists.

The growing disease burden, a focus on transplantation as the preferred treatment for ESRD, and limited staffing in both dialysis and transplant centers has resulted in the current push to get patients referred for transplant evaluation. To provide the same level of support for all patients, equal access and treatment has been the goal. Revising education and referral practices would involve a more patient-focused collaboration between the referring dialysis and transplant centers. Understanding that *Shifting Life's Focus* means that each life is different and each patient will approach the option of transplantation differently is important. Based on this theory, education and referral practices would need to change to address each patient individually. Instead of making sure that patients get referred and start their workup, the dialysis unit and referring nephrologists would revise their practice to have a more individualized approach with each and every patient.

**Tailor the completion of the transplant evaluation into phases that can be analyzed and measured for effectiveness.** The transplant evaluation process should be divided into phases that are guided by the concepts in the framework. These phases will repeatedly focus on understanding and planning to make choices in an orderly manner. Expensive resources (such as cardiac stress testing) and limited resources (such as physician availability) will be expended when the initial phases are completed. Tailoring the evaluation process in consideration of the theory *Shifting Life's Focus* could proceed in incremental phases.

***Phase 1:*** Introductory assessment (to include decision-making) and education about the evaluation process, working with the transplant team, establishing and

maintaining communications. Testing for standard health maintenance (colonoscopy, mammogram, Pap smear, dental).

**Phase 2:** Basic clinical evaluation from current providers, additional education about the testing required during the next phases of the evaluation process, discussion about financial aspects of evaluation testing, and information on living with a transplant. Education about making choices during the evaluation process. Assessment of chronic health conditions.

**Phase 3:** Meet with the entire transplant team, education about after transplant, and scheduling of final testing (cardiac stress test, CT scans, etc.) Discuss types of donors and re-address financial preparation for transplant.

**Develop and implement a peer mentoring program for dialysis patients who initiate transplant evaluation.** A dialysis patient who has successfully completed his or her transplant evaluation, and who has similar financial and lifestyle experiences could be educated and prepared to be a mentor to other patients in the dialysis unit. These mentors would work collaboratively with (and under the supervision of) the transplant liaison in the dialysis unit and the transplant coordinator in the transplant center to assist peers along the transformation pathway through their transplant evaluation. Peer mentors would help support the teaching and reinforce the evaluation process and the understanding of choices being made along the way.

### **Recommendations for Future Study**

Based upon the review of the literature, this study is the first to explore patient's experiences with transplant evaluation from a qualitative, grounded theory perspective.

This study has developed a substantive theory of *Shifting Life's Focus* that should be expanded through additional qualitative and quantitative investigation.

Recommendations for future study include examining the concepts developed using both qualitative and quantitative approaches, broadening the review of concepts related to family support issues, examining dialysis patient's perceived trust in unknown (transplant) providers, and exploring existing supportive relationships to dialysis patients further. Continuing to develop the theory through additional participant interviews and expanding the research team to include cultural diversity in its members would add depth to the preliminary proposed theory. Additionally, a study examining aspects of decision-making and health beliefs in dialysis patients may support the development of a framework for future study. Continuing to examine racial aspects of health care beliefs and health care delivery effectiveness will allow full understanding of health disparities and may provide clinicians with helpful recommendations to assure equitable and culturally sensitive care.

### **Conclusion**

In conclusion, this study examined the experiences of African American dialysis patients undergoing evaluation for kidney transplantation. The analysis of interviews with these participants led to development of the theory *Shifting Life's Focus*, centered on themes of financial concerns, complex chronic health conditions, and following through. This study represents the beginning of theory development in a very important area of health care. Dialysis and kidney transplantation are significant areas of growing disease burden, racial equity concerns, and financial expense to the national health care system.

Better understanding of how the proposed theory can be used to understand and improve patients' experiences may provide more equitable access to treatment for African American dialysis patients.



# APPENDIX A. DESCRIPTION OF THE STUDY PARTICIPANTS

Name	Gender	Age	Length of time on dialysis	Education	Insurance	Combined family income
Sam	Male	39	6 years	Some HS	Medicare and MA	<\$25,000/yr.
Tom	Male	52	6 years	Completed HS	Medicare and MA	<\$25,000/yr.
David	Male	64	7 years	Some college	Medicare and private insurance	\$25,000-\$50,000/yr.
Pam	Female	52	2.5 years	6 <sup>th</sup> grade	Medicare and MA	<\$25,000/yr.
Shirley	Female	59	9 years	Completed HS	Medicare and MA	<\$25,000/yr.
Jennifer	Female	52	2.5 years	Some HS	Medicare	<\$25,000/yr.
Larry	Male	55	10.5 years	Some HS	Medicare and MA	<\$25,000/yr.
Beckett	Male	44	13 years	Some college	Medicare and MA	<\$25,000/yr.
Sarah	Female	59	3.5 years	Some HS	Medicare	<\$25,000/yr.

HS= High School    MA= Maryland Medicaid (Medical Assistance)

## APPENDIX B. STANDARD TRANSPLANT EVALUATION TESTING

Cardiac Stress Test

Echocardiogram

EKG

Abdominal CT scan

Carotid Ultrasound

Gynecological Exam with Pap Smear

Mammogram (40 or over)

Colonoscopy (50 or over)

Blood serologic testing

Hepatologist consult and liver biopsy (if Hepatitis C positive)

Chest X Ray

Pulmonary Function Testing (if significant smoking history)

Blood testing

PPD testing (TB skin test)

## APPENDIX C. SUMMARY OF MEDICARE COVERAGE FOR DIALYSIS AND KIDNEY TRANSPLANTATION

All patients had met eligibility for Medicare through either enough work history (and paying into Medicare) or having a spouse who was eligible. Medicare coverage for dialysis begins the fourth month of regular dialysis treatments, and becomes the primary payer after 30 months on dialysis. All of the participants had been on dialysis more than 30 months, and were covered by Medicare. Medicare Part A is provided at no charge. Medicare Part B, which covers most outpatient procedures, physician services, and some the cost of anti-rejection drugs following transplant, must be paid for by patients who want/need the additional coverage. In addition to this, a Medicare drug plan (Part D) will be required in order to have adequate coverage for all post transplant medications. Medicaid, the state program that assists with medical bills for low income people who meet the eligibility requirements, has a plan for covering the costs (such as Part B, Part D, and deductibles) that Medicare does not cover. Whereas Medicare (and in some cases Medicaid) will continue to pay for dialysis services for life, coverage for care following kidney transplantation ends at thirty months post-transplant unless the patient is disabled for reasons other than kidney failure.

## APPENDIX D. JOHNS HOPKINS IRB APPROVAL

Page 1 of 1



Office of Human Subjects Research  
Institutional Review Boards  
Johns Hopkins University, 3535 North Charles Street, Room 8-120  
Baltimore, Maryland 21205-5181  
410-516-7500  
ohs@jhmi.edu  
www.jhmi.edu/ohs

Dated March 2, 2010

### NEW APPLICATION APPROVAL

Review Type: Expedited  
PI Name: MARIE NOLAN  
Study #: RA\_00016048  
Study Name: Experience with Kidney Transplant Evaluation: The African American Perspective  
Committee Chair: LAURA BOCCO  
Committee: JHIM-IRB X

Date of approval: February 25, 2010

Date of expiration: February 23, 2011

The JHIM IRB approved the above-referenced New Application.

**Date of Approval and Expiration Dates:** The approval and expiration date for this research are listed above. If the approval lapses, the research must stop and you must submit a request to the IRB to determine whether it is in the best interests of individual participants to continue with treatment interventions.

**Changes in Research:** All proposed changes to the research must be submitted using an eIRB Change in Research Application. The changes must be approved by the JHIM IRB prior to implementation, with the following exception: changes made to eliminate apparent immediate hazards to participants may be made immediately, and promptly reported to the JHIM IRB.

**Continuing Reviews:** Continuing Review Applications should be submitted at least 6 weeks prior to the study expiration date. Failure to allow sufficient time for review may result in a lapse of approval. If the Continuing Review Application is not submitted prior to the expiration date, your study will be terminated and a New Application must be submitted to reinstate the research.

**Unanticipated Problems:** You must inform the IRB of any unanticipated problems involving risks to participants or others.

#### **Study documents**

**Written Consent:**  
FINAL\_Notes\_RA\_00016048\_CV\_022510\_Nolan.doc

**Recruitment Materials:**  
FINAL\_Notes\_RA\_00016048\_Recruitment flyer\_022510\_Nolan.doc

**Protocol:**  
EXPERIENCE WITH KIDNEY TRANSPLANT EVALUATIONS.02.09[1].doc

**Study Team Members:**  
HAMID RAH, SUSAN HUMPHREYS

<http://e-irb.jhmi.edu/irb/Doc/0/TS5NPKEUT4S#HT#035MLM9CR67/fromString.html>

3/5/2010

## APPENDIX E. RECRUITMENT FLYER

### **Will you tell me about your experience with Transplant Evaluation??**

**African Americans who are on dialysis needed for a  
research study**

#### **What is involved?**

- **Filling out a questionnaire**
- **Answering questions during an interview with a  
nurse about your experiences and your thoughts  
about transplant and the transplant evaluation**
- **Two interviews**

#### **How can I join?**

- **Tell your dialysis nurse**
- **Contact Susan Humphreys MS, RN at 440-858-2585**

Application No: NA\_00016042  
PI: Marie T. Nolan, PhD, RN



## APPENDIX F. CONSENT FORM



Approved February 25, 2010

Date: February 23, 2010  
Principal Investigator: Marie T. Nolan, PhD, RN  
Application No. NA\_00016048

Site of Research:  
Johns Hopkins Medical Institutions



### RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM

Protocol Title: Experience with Kidney Transplant Evaluation- The African  
American Perspective

Application No.: NA\_00016048

Principal Investigator: Marie T. Nolan, PhD, RN

1. **What you should know about this study:**
  - You are being asked to join a research study.
  - This consent form explains the research study and your part in the study.
  - Please read it carefully and take as much time as you need.
  - Please ask questions at any time about anything you do not understand.
  - You are a volunteer. If you join the study, you can change your mind later. You can decide not to take part or you can quit at any time. There will be no penalty or loss of benefits if you decide to quit the study.
  - During the study we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.
  - Ask your study doctor or the study team to explain any words or information in this informed consent that you do not understand.
2. **Why is this research being done?**

This research is being done to learn about the experiences of African Americans with kidney failure as they are evaluated for transplant.

Chronic kidney disease is a global health problem, especially among African Americans. In the U.S., African Americans with kidney failure who are on dialysis are less likely to have a kidney transplant compared to Caucasian Americans. The reason for this difference is not well understood.

You are being invited to take part in this study because you have been referred for an evaluation for possible kidney transplantation.

**How many people will be in this study?**  
A total of twenty (20) people will be able to join this study.
3. **What will happen if you join this study?**

If you agree to be in this study, we will ask you to do the following things:



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Application No: NA\_00014048

- Complete a questionnaire
- Participate in two interviews about your transplant evaluation experience. These interviews will be spaced apart by about one month. After each interview is transcribed into writing, you will be asked to read (or have read to you) the transcript to make sure that you were heard correctly. If it is convenient for you, the interviews will be held at your dialysis center, while you are on dialysis. If you prefer, the interviews can be held over the phone, or in a location other than the dialysis center.
- The interviews will be audio-taped with your permission.  
Do you agree to be audiotaped?    yes    no

**Future research**

We would like your permission to contact you about other studies that you may be eligible for in the future. Please initial your choice below:

- \_\_\_\_\_ Yes, you may contact me in the future about other studies related the experience with transplantation evaluation and transplantation.
- \_\_\_\_\_ No, I do not want you to contact me about other studies

**How long will you be in the study?**

You will be in this study for eight weeks.

**4. What are the risks or discomforts of the study?**

There are no risks to your physical health and comfort, however discussion about this subject may cause some people to feel anxious or distressed.

The researcher may ask sensitive questions about your positive or negative experiences related to your health care in the past.

You may get tired or bored when you are asked questions or you are completing questionnaires. You do not have to answer any question you do not want to answer.

There is the risk that information about you may become known to people outside this study.

**5. Are there benefits to being in the study?**

There is no direct benefit to you from being in this study.

If you take part in the study, your responses may help us to help others who have a transplant evaluation in the future.

**6. What are your options if you do not want to be in the study?**

You do not have to join this study. If you do not join, your care at Johns Hopkins will not be affected.

**7. Will it cost you anything to be in this study?**

It will not cost you anything to be in this study.

**8. Will you be paid if you join this study?**

You will not be paid to be in this study.



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**9. Can you leave the study early?**

- You can agree to be in the study now and change your mind later.
- If you wish to stop, please tell us right away.
- Leaving this study early will not stop you from getting regular medical care.
- If you leave the study early, Johns Hopkins may use or give out your health information that it already has if the information is needed for this study or any follow-up activities.

**10. Why might we take you out of the study early?**

You may be taken out of the study if:

- Staying in the study would be harmful.
- You fail to follow instructions.
- The study is cancelled.
- There may be other reasons to take you out of the study that we do not know at this time.

**11. How will your privacy be protected?**

Johns Hopkins has rules to protect information about you. Federal and state laws also protect your privacy. This part of the consent form tells you what information about you may be collected in this study and who might see or use it.

Generally, only people on the research team will know that you are in the research study and will see your information. However, there are a few exceptions that are listed later in this section of the consent form.

The people working on the study will collect information about you. This includes things learned from the procedures described in this consent form. They may collect other information including your name, address, date of birth, and other details.

The research team will need to see your information. Sometimes other people at Johns Hopkins may see or give out your information. These include people who review the research studies, their staff, lawyers, or other Johns Hopkins staff.

People outside of Johns Hopkins may need to see your information for this study. Examples include government groups (such as the Food and Drug Administration), safety monitors, other hospitals in the study and companies that sponsor the study.

We cannot do this study without your permission to use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study.

We will use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside Hopkins who receive your information may not be covered by this promise. We try to make sure that everyone who needs to see your information keeps it confidential – but we cannot guarantee this.

The use and disclosure of your information has no time limit. You can cancel your permission to use and disclose your information at any time by calling the Johns Hopkins Privacy Officer at 410-735-6399 or by sending a letter to:





Date: February 13, 2010  
Principal Investigator: Maria T. Nolan, PhD, RN  
Application No: MA\_P0014948

Johns Hopkins Privacy Officer  
5801 South Avenue  
McAuley Hall, Suite 310  
Baltimore, MD 21209  
Fax: 410 955-6521

Please be sure to include the name of the principal investigator, the study number and your contact information.

If you do cancel your permission to use and disclose your information, your part in this study will end and no further information about you will be collected. Your cancellation would not affect information already collected in this study.

**12. What other things should you know about this research study?**

**a. What is the Institutional Review Board (IRB) and how does it protect you?**

The Johns Hopkins Medicine IRB is made up of:

- Doctors
- Nurses
- Ethicists
- Non-scientists
- and people from the local community

The IRB reviews human research studies. It protects the rights and welfare of the people taking part in those studies. You may contact the IRB if you have questions about your rights as a participant or if you think you have not been treated fairly. The IRB office number is 410-955-3008. You may also call this number for other questions, concerns or complaints about the research.

**b. What do you do if you have questions about the study?**

Call the principal investigator, Dr. Nolan at 410-502-1535. If you wish to talk to someone else, call the IRB office at 410-955-3008.

**c. What happens to Data that are collected in the study?**

Scientists at Johns Hopkins work to find the causes and cures of disease. The data collected from you during this study are important to both this study and to future research.

If you join this study:

- You will not own the data given by you to the investigators for this research.
- Both Johns Hopkins and any sponsor of this research may study your data collected from you.
- If data are in a form that identifies you, Johns Hopkins may use them for future research only with your consent or IRB approval.
- You will not own any product or idea created by the researchers working on this study.
- You will not receive any financial benefit from the creation, use or sale of such a product or idea.

**d. What are the Organizations that are part of Johns Hopkins?**

Johns Hopkins includes the following:

- The Johns Hopkins University
- The Johns Hopkins Hospital
- Johns Hopkins Bayview Medical Center
- Howard County General Hospital
- Johns Hopkins Community Physicians



Date: February 25, 2010  
Principal Investigator: Maria T. Hahn, PhD, RN  
Approvers: No: NA\_00016042

**13. What does your signature on this consent form mean?**

Your signature on this form means that:

- you understand the information given to you in this form
- you accept the provisions in the form
- you agree to join the study

You will not give up any legal rights by signing this consent form.

**WE WILL GIVE YOU A COPY OF THIS SIGNED AND DATED CONSENT FORM**

_____ Signature of Participant	_____ Date
_____ Signature of Person Obtaining Consent	_____ Date

**NOTE: A COPY OF THE SIGNED, DATED CONSENT FORM MUST BE KEPT BY THE PRINCIPAL INVESTIGATOR; A COPY MUST BE GIVEN TO THE PARTICIPANT; AND, IF APPROPRIATE A COPY OF THE CONSENT FORM MUST BE PLACED IN THE PARTICIPANT'S MEDICAL RECORD.**

## APPENDIX G. INTERVIEW GUIDE

### **Interview 1.**

#### **Goals: 1. Establish rapport with the patient**

Initial small talk about things in the dialysis unit, how their day has been, what they might do after dialysis, how they are feeling today as compared to their usual state of health.

Reinforce the importance of confidentiality about the interview and ask the patient if they are comfortable with being audiotaped. The benefit of the audiotape is that I can listen to them carefully and get everything they say down verbatim. I want to make sure the patient is comfortable with this (being audiotaped) and will offer them that at any time they want to talk with the tape recorder off, I will take notes (and turn off the tape recorder). I expect that most of the first interview will be establishing rapport and getting the patient to “warm up”.

With the patient’s approval, I will audiotape the interview.

#### **2. Summarize the purpose of the study**

“The reason that I am doing this study is to understand the experiences that African American patients (being evaluated for kidney transplantation) have. I want to know if there are aspects about the evaluation process, or beliefs and understandings that patients have that might interfere with getting a transplant or getting on the list.

- What do you think about that?

“Please feel free to tell me what you really feel and know, not what you think a nurse wants to hear. This study is about the patient’s real feelings and experience with transplant evaluation. There are no right answers to the questions I will ask you”.

#### **3. Explore where the patient is in the process of transplant evaluation.**

*“Can we talk about your experience so far with transplant evaluation?”*

- *When did you first consider a transplant?*
- *Who referred you to the transplant center?*
- *Did you have to wait long for an appointment? Why?*
- *What was it like to meet with the transplant team?*
- *How did you feel about that experience? How were you treated?*

- *Were there any concerns or questions that you didn't feel like you could talk about? Why?*
- *What are the next steps? What does that mean to you?*
- *Is there anything else you would like to talk about related to your transplant evaluation or getting a transplant?*

#### **4. Provide background information about kidney disease and kidney transplantation in African Americans.**

*"Some research has shown that African Americans (as compared to whites) experience more kidney failure but are less likely to be referred for a kidney transplant.. Another study showed that African American patients who were referred for a kidney transplant were less likely than whites to complete the evaluation".*

- *Have you heard about this or do you know it to be true?*

#### **5. Set the stage for the follow up interview**

The next time that we will talk will be in about a month. I can either contact you on the phone or come back to the dialysis unit. Which do you prefer?

*I will be asking more questions about your transplant evaluation and how the process is going at our next interview.*

#### **Interview 2.**

**Goal 1. Establish rapport with the patient (again), discuss the purpose of the study and review the previous interview transcription for the patient to allow the patient to make sure that I have understood them correctly and stated the wording accurately.**

Initial small talk about things in the dialysis unit, how their day has been, what they might do after dialysis, how they are feeling today as compared to their usual state of health.

*"When we met the last time I explained that I am doing this study is to understand the experiences that African American patients (being evaluated for kidney transplantation) have. I want to know if there are aspects about how the process of evaluation is carried out, or beliefs and understandings that patients have, that might interfere with success in getting a transplant or getting on the list.*

We will talk about your transplant evaluation more today as well as your thoughts and beliefs about your kidney disease and health care. I wanted to remind you that if at any time, you want to talk without being taped, I will turn off the tape and just take notes.

I brought the transcribed notes from the last interview and would like to go over them with you and make sure I have heard you correctly.”

***Goal 2. Review the previous interview transcription with the patient (member-checking).***

This is very helpful, thank you very much. Do you want to talk more about something that you said the last time?

***Goal 3. Explore specific experiences in which the patient has found difficult related to getting to transplantation.***

The last time we met, we talked about your initial experiences with the transplant program. How has the evaluation been proceeding over the past month?

Can you talk more about experiences or things you have been asked to do?

Are there things you need to do that you have found difficult in the process of getting your transplant evaluation or care?

Do you have any thoughts on why African Americans are less frequently referred for kidney transplant and are less likely to finish the evaluation to get on the list?

***Goal 4. Explore the patient's beliefs about transplantation***

“Now that you have learned more about this process, what are your thoughts about getting a kidney (receiving a transplant)? Do you have any concerns about your care during or after the transplant? Why?

What are your thoughts about the kidney donor (person who would give the kidney-either a deceased person or living donor)?

Do you think that the way donor organs are distributed is fair to African Americans and whites equally?

Is it fair to African Americans and whites equally?

Do you have any religious or faith-based beliefs that are in conflict with organ donation or organ transplant?

Do you think that getting a transplant is in any way an experiment or something that is not truly proven to be effective? In other words, do you equate transplant with research or experimentation?

Is there anything further that you would like to share about your beliefs about organ transplant, or organ donation,

## APPENDIX H. DAVITA STUDY APPROVAL



### Study Approval Terms

Study Code
021-2010


<b>Principal Investigator</b>	<b>Principal Investigator's Institution</b>
Maria Nolan PhD RN	Johns Hopkins University School of Nursing
<b>Study Title</b>	
"Experience with Kidney Transplant Evaluation: The African American Perspective"	
<b>Protocol</b>	
N/A	
<b>Criteria</b>	<b>Comments</b>
<b>Approval Date</b>	August 5, 2010
<b>Length of the Study</b>	8 weeks per patient
<b>Facility(s) Approved (name and number)</b>	<ul style="list-style-type: none"> <li>DaVita JB Zachary (#6040)</li> <li>DaVita 25<sup>th</sup> Street (#0325)</li> <li>JHHS-North Bond Street (#3262)</li> </ul>
<b>Number of Patients</b>	20 patients
<b>Staff Tasks/Responsibilities</b>	<ul style="list-style-type: none"> <li>According to the attached Charge Master, DaVita Staff will identify and recruit potential candidates for the trial. All activities related to the study, must be performed by investigator or investigator's research staff.</li> <li>Per applicable state and/or federal laws as well as any DaVita policy and procedure, written or verbal physician orders must be obtained prior to ending or starting any agents and/or study drugs or related therapies.</li> <li>Any protocol amendments after initial study approval must be reported and sent to DCR for review.</li> <li>Any ICF revisions made after initial study approval must be sent to DCR for review.</li> <li>If the PI plans to exceed the anticipated number of patients referenced on this form, DCR must be notified prior to enrolling additional patients.</li> <li>Any SAEs that are probably or possibly related to the study article must be reported to DCR as soon as is practically possible.</li> <li>A signed copy of the patient's ICF must be placed in patient's chart as well as any amended ICF's or HIPPA release forms.</li> <li>A copy of the protocol must be made available to the dialysis unit staff.</li> <li>PI is accountable for ensuring timely documentation of applicable study activities into the Clinical Trials Management System (CTMS) regardless of whether there are study charges. PI will be invoiced monthly by DCR as work is performed and reported.</li> </ul>

## APPENDIX I. GEORGE MASON UNIVERSITY HSRB APPROVAL



Office of Research Subject Protections  
Research Building, 4400 University Blvd., S2-900, Arlington, Virginia 22204  
Phone: 703-691-4615; Fax: 703-691-9780

TO: Ann Moore, College of Health and Human Services

FROM: Sandra M. Stuebel, RN, MSN, CIP,   
Director, Office of Research Subject Protections

PROTOCOL NO.: 6767 Research Category: Doctoral Dissertation

PROPOSAL NO.: N/A

TITLE: Experience with Kidney Transplant Evaluation-The African American Perspective

DATE: June 16, 2010

Co: Susan Humphreys

On 6/16/2010, the George Mason University Human Subjects Review Board (GMU HSRB) reviewed and approved the above-cited protocol following expedited review procedures.

Please note the following:

1. Any modification to your research (including the protocol, consent, advertisements, instruments, funding, etc.) must be submitted to the Office of Research Subject Protections for review and approval prior to implementation.
2. Any adverse events or anticipated problems involving risks to subjects including problems involving confidentiality of the data identifying the participants must be reported to Office of Research Subject Protections and reviewed by the HSRB.

The expiry date of this study is 6/16/2011. You may not collect data beyond that date without GMU HSRB approval. A continuing review form must be completed and submitted to the Office of Research Subject Protections 30 days prior to the anniversary date or upon completion of the project. A copy of the continuing review form is attached. In addition, prior to that date, the Office of Research Subject Protections will send you a reminder regarding continuing review procedures.

If you have any questions, please do not hesitate to contact me at 703-693-4615.

## APPENDIX J. DEMOGRAPHIC QUESTIONNAIRE

### KIDNEY TRANSPLANT EVALUATION-THE AFRICAN AMERICAN PERSPECTIVE

#### Screening/Demographic Questionnaire

Please circle the category that best describes you. Thank you.

<b>Age</b>	18-25	<b>Gender</b>	Male	Female
	26-40	<b>Race</b>	African American	
	41-60		Caucasian	
	61 and older		Other	

**Length of time on dialysis**

6 months or less	7 months to 1 year
1-2 years	
More than 2 years	

**Type of insurance** (circle more than one if more than one applies to you)

Medicare	Private Insurance
Maryland Medical Assistance	No insurance
Other	

**Level of education**

some High School
Completed High School
Some College
Completed College degree
Graduate school

**What is your combined family income?**

Less than \$25,000 a year
\$25,001.-\$50,000 a year
\$50,001.-\$75,000 a year



<b>Are you being evaluated for kidney transplant?</b>	<b>Yes</b>	<b>No</b>
<b>Have you had a kidney transplant in the past?</b>	<b>Yes</b>	<b>No</b>

## APPENDIX K. PARTICIPANT INTERVIEWS

### Sam: Interview 1

*OK, so, um...this is really the first interview and I start out by summarizing the purpose of the study...*

*I want to know your beliefs, and your perceptions. So, what are your just general beliefs about that?*

**Well, it's not a problem. You know I just think that certain...it's just good for certain people. You gonna need a lot of support..you know you need your family support or you need some kind of support because there's going to be obstacles that come up, you know you got money situations and just different things. I know that, um, I was going this time for the evaluation and I found out that after a year, you know, that there are no benefits no more. I can understand the.....I think that, you know it all depend on your background. If you come from a situation where you already had a job, a good job with good benefits, you know, you would be alright and you could get back into that field, you would be alright.**

*Tell me about the "one year". You said that you found out that after a year....*

**Yeah, that you know you don't have the Medical Assistance and the Medicare, and you have to take all this medication in order for the kidney to work...**

**So, my concern was how am I going to pay for all of this medication, you know... in a year's time. Once they give you six months and they see how it is taking, you know the next six months....You know it's just something that I found out going to the evaluation**

*Yes,*

**I know I didn't know that before. So it's just different things and it would be good, you know, if you had the support.**

*Tell me a little bit about support. There are all kinds of support...what kind of support?*

**Any kind of support...will help you, you know, deal with the issues after the transplant.**

*So it's the insurance and the financial support.*

**Yeah, well I'm looking at it, you know a year's time....say they give you six months to recover and then the next six months they drop you. If you go out and get a new job the benefits don't kick in...you got to wait another 3 to 6 months before you even get benefits from this new job you are starting...I am just seeing that one point right there and I really don't think that it's enough time, or if you had certain steps from before you had the transplant and you got set up to deal with these things afterword, I think that would be good.**

*And that is what you meant by....it depends on your background. It depends on who you are....*

**Yeah, and um as far as working a job with good benefits and all that .....still you don't have benefits right away. But then again, I don't know...some jobs you do get benefits right away, but not the kind of jobs I qualify for.**

*What kind of jobs do you have experience knowing about?*

**Labor, um**

*Labor...*

**You know I didn't really graduate you know so, and didn't get my GED so, you know so therefore that tells you what kind of jobs I could get or jobs that I had. No corporate job...maybe they might get benefits right away..I don't know, not the kind of job that I did work at or get....in the past. That's even if they have benefits**

*Right, a lot of jobs come without benefits now days*

**Well, especially the kind of jobs that I qualify for, you know?**

*Can we talk about your experience with the actual evaluation?*

*When did you first consider a transplant?*

**Well, in 2005 when I first got on dialysis, you know, they talk to you about, you know, about me being young, and you know I could still be able to work and stuff,.....so, I really had no problems with the evaluation. You know I went there, you know they drew the blood work,**

*When was that? Do you remember when you went?*

**No, I don't**

*Ok,*

**Just, I done it again...**

*So you started it and then you started it over again?*

**Well, the first time I started it and I really got discouraged. I felt like it really wasn't something that I wanted to do.**

*From the very first?*

**The first time**

*Um, did you have to wait a long time for the appointment?*

**No**

*So what discouraged you?*

**Well, it had nothing really to do with..just things with myself**

*So it was not the evaluation it was dealing with things with yourself?*

**No, I don't think so, I don't think they don't really ask for too much if that is something that you really want to do.**

*Was there a family member or a friend who you involved in your decision to go for a transplant?*

**Well, I really don't...I really don't you know my family....I really don't have a lot of family**

*Or a friend, or was there anybody that encouraged you, or...*

**That encouraged me to get the transplant?**

*Right*

**No, it was probably just something**

*Something that you did on your own?*

**I probably talked to my social worker.**

*Your social worker here...so was she the one that referred you*

**Yeah, it was from the clinic, they started me on the process.**

*OK..*

*So, what was your experience, like meeting with the transplant people themselves?*

**Oh, it was fine**

*And how do you feel that you were treated there?*

**I was treated fine; I mean I had no problems with that.**

*OK*

**I mean they informed me of what was going on and what was going to be expected, and how everything was going to go. And the main this was just doing the blood work...getting the blood. Other than that...**

*So were there any things that they brought up during the evaluation that you didn't want to talk about?*

**No**

*No, not at all...that was not a problem...ok.. So, some studies have shown that AA as compared to whites experience more kidney failure but are less likely to be referred.....Have you heard about this or do you know this to be true.*

**No, I haven't heard, but I can...I haven't heard but it just falls back on what I was saying in the beginning. You know a lot of African Americans may not have you know, the education, I really don't think it's that either because there are plenty of white Americans who just graduated.... and they are not in the same situation because they have all kinds of support, you know, or other things,**

*So you think it might have to do more with the*

**With the family...the support system...and the job background, whatever...has something to do with it but I don't really know the statistics,...of how many African Americans have dead end jobs as compared to how many white Americans have dead end jobs.**

*But what are your beliefs, though, without the statistics?*

**I would believe, you know, that you all, that white Americans do have opportunities and better job uh, what is the word I am looking for...opportunities...**

*Better job opportunities?*

**Yeh,**

*Better supports in general?*

**Maybe. Because, you know in the black household there are a lot of broken families. I really can't say a lot because I can only just speak for myself.**

*OK, um....so really this....I don't have additional questions. I just wanted to bring up the topics. The next time I will bring you back what you said in detail....just try to*

**Because like, you know I was going through it and everything, and I was going a little further you know that I did the first time. That was when they told me about after the year, what am I going to do? What is the use of my going and getting this transplant knowing that I have to take this medicine in order for the transplant to be successful.**

*Right*

**But I know that where I am at right now I probably wouldn't afford the medication.**

*So would it be Medicaid that after a year would not pay?*

**From what I am told it is everything. It's really not a big deal. I know I could find a job within a year making more than I am getting from them, but as far as to be able to afford to pay to live and to be able to afford to pay for this medication...honestly the type of job I could be able to get and the way I live now...you know, it would probably be just enough to pay my bills. I just think, you know that should go into the evaluation process as far as, you know, and maybe that would be like you were saying....not what you said but what you questioned that African Americans are treated different in terms of getting referred....maybe a lot of us don't fit the criteria, you know...**

*Umhum...*

**Especially as far as.....You know I really didn't want to do it from the get-go but I let you know, my social work is really good. I just tried and .....why take the chance and not be able to get the medication and the kidney failed and somebody else could have got it and been able to do what they needed to do when they get it, you know...but you know...that's just life.**

*Yeah, that whole medication thing....I think it is an eye-opener.*

**Then at the same token they give you the booklet with the prices, so I'm .....**

*The cost of the medication is ridiculous...*

**I know, and the amount of the medication that you need to take...and then you would have to have a really good job with really good benefits to pay for all of that stuff.**

*Even just the co- pays...if you had only Medicare and it only paid 80%*

**Well, yeah...it still would be...**

*Well the 20% is still a lot of money*

**When you still need a lot of medication. Well I heard they worked a lot of ways where they get it down so you don't have to take so much.**

*And they have worked on legislation to pay longer...but even if they paid 80% for life the 20% is a lot of cost*

**Yeh, but still ....better than paying 100%**

*Correct...*

*I really don't have any other questions. I will have a lot more the next time. Is there anything else you want to say?*

**No**

*I think the next time I would like to go into more of what we talked about talking about your decision making process and talk about how people make the decisions....*

**We can talk about that...as far as my decision making? Well from the beginning I just looked at it. I think a lot of other people....well I can't talk about other people, but just me myself, you know I am just a strong believer that, you know, when it's my time to leave this earth, it's my time to leave. And I really don't think that getting a transplant is going to prolong that.**

*You don't think it is going to prolong it..*

*At this point the machine alarmed and the staff requested I stop the interview. I said good bye to the patient.*

Sam: Interview 2

*My intro.....*

*Have there been any changes in the last month in terms of your transplant evaluation, being contacted by the transplant center or trying to contact the transplant center?*

*Q13*

**Yeah, they contact me all the time about the stuff that I still need to get done, to finish the process. So, they pretty much do that.**

*They contact you?*

**The decision I made myself not to go through with it at this time.**

*So, did you tell them that?*

**Well, no not really because they keep trying to get me to finish regardless. They are pretty persistent and they call a lot to remind me of what I need to finish in terms of testing. Especially with me being young and stuff.**

*So they contact you to try to get you finish up the testing?*

**And they also call my social worker, and she will come and talk to me about it. And they send stuff in the mail too.**

*So have you decided to stop the process, but you haven't really told them?*

**Yeah, well before, you know, this is my second time, you know, but once you don't do the things you need to do over a certain amount of time they stop contacting you. One of the techs here will talk with patients and try to encourage them, you know, about the process, and the social worker does as well.**

*So you are still going along with it but you are personally still feeling it is not for you?*

**Well, in the beginning, you know, I had some thoughts about it, then I changed my mind, and then I thought about it again. It's like the time, me trying, and it's like for me there's no family.**

*Yeah.*

**Well, you know they tell you 'you need to do that because it's the thing to do'. You know what I'm saying. And some of the people here It's 'so on and so on'.**

*The last time we talked we talked about whether a friend or family member was involved in your decision to pursue a kidney transplant. And you really talked about that a lot as being one reason why you didn't want to move forward because you really didn't have the support...*

**Oh, the support, well basically that was about, you know, financially. I'm saying you really need financial support in terms of that. But um,**

*So it's more financial support?*

**With me, yeah, and you know I, um I mean I would need the financial support from somewhere until I'm back and able to work and help with getting the medications. When it comes to the point when the benefit is not paying for that anymore I would need that support.**

*What about the people support? Can you tell me about the people in your life that might help you; You know anybody that you think is important to you to make important life decisions...*

**Um, well I don't really have any people like that in my family- it's not really close knit. So, you know everybody is basically doing their own thing, you know. And um, that's pretty much it**

*So you don't talk to somebody about this decision.*

**Yeah, like maybe a friend or a girlfriend or something like that, Yeah, it's mostly like friends in general.**

*So, you are closer to your friends?*

**Yeah, well that's normally how it goes when you don't have a close knit family.**

*That is true, that is right.*

**You meet nice people and they are good friends and you try to keep them in your circle.**

*So do you have a girlfriend now?*

**Yeah.**

*Do you have a pretty close network of friends?*

**Yeah, a few of them. There's a few friends.**

*So do you talk to your girlfriend about your illness at all?*

**Yeah, I was dealing with her from even before I had the situation.**

*So have you been together for a while?*

**Yeah, off and on. So she pretty much knows what is going on.**

*Um, so I guess my next question is now that you have learned more about the transplant process, what your thoughts about getting a kidney...and I guess your thoughts are still that it's not for you right now?*

**It's not really that, it's that um, things come up along the way. You know like I said that you need that financial support. Even when you think everything is cool and going to be OK, there are still things that come up along the way that you are going to need money.**

*Money is tight*

**Well my decision wasn't all the way made, you know I was going through it...I was going through it but I got at one point where if there was a financial situation that I couldn't take care of and I really don't know nobody that I could go to, you know. I got this girlfriend but she is struggling too, you know she is a single parent so she is struggling and I am struggling and I really don't have people that I can just call up when I have a need like that.**

*I understand. I think some people think that the transplant is a quick fix and it will fix everything but you seem to have a pretty deep understanding of the responsibilities. How do you think you got that? By going through the process and talking to people or what?*

**No, that's just the kind of person I am. I try to think things out before I make decisions. It's not jump into things.**

*What are your thoughts about the kidney donor?*

**What's my thoughts about the donor? I think it's a good thing...I'm a donor myself. Even though I might not get a transplant if I can help somebody else who**

might want to go down that road, then why not. I mean I'm here I'm not going to need the organs.

**You talking about the living donor?**

*No, I am talking about either...a living donor or a deceased donor.*

**It's a good thing that people do that. If you can help somebody out then why not?**

*Have you ever know somebody who got a kidney from a friend or a family member?*

**No, or if they did I don't know that. People that I have met after the fact that was on dialysis and got transplanted I don't really know where their donor came from. Do you think that the way donor organs is distributed is fair for African Americans and whites equally?**

*Um, I really don't know. That's a hard question to answer unless you know how many organs are coming in and where they're going and who is getting them. That's kind of hard to answer. But I see people get transplants, you know here in my clinic, and they're all black people in here, so.. but the rate towards the predominately white clinic and whether or not they are having family donate, I don't know.*

*Do you have any religious or faith-based beliefs that are in conflict with organ donation or organ transplant?*

**Well, not really religious, just beliefs of my own. I am a strong believer that when it's your time to go you are going to go transplant or not, you know, I am just a believer that when your number is called you are going to go.**

*So you don't see any conflicts with your beliefs and transplant?*

**No, not me.**

*Do you think that getting a transplant is in any way an experiment.....*

**NO, I don't. I don't have no reason to believe that.**

*Is there anything that I did not ask you about organ transplant or organ donation that you want to add?*

**Not right now. Nothing on the top of my mind.**

*Um, (pause) OK,*

*Would you have any concerns about your care if you were to receive a transplant....after receiving a transplant?*

**No, they told me that for a while you have to have somebody with you to make sure you recover and I don't have any problems with that.**

*Those are all of my standard questions. Did I not ask you something?*

**Well, if something comes in my mind I will let you know when you call me (to go over the transcription).**

*What's a good time to call you?*

**Well, anytime is good. You have got my home number. If I am not there just leave a message and I will get back with you. I'm pretty much home a lot.**

*OK, so there is not anything I didn't ask you that you want to talk about transplant or donation or anything?*

**No because in the beginning I was thinking of something else when you asked me about it which I pretty much covered in here. WE covered the first time. So this time we got to what it's really about, like do I think there is any, um setbacks. Not**



setbacks but things different for African Americans trying to get a transplant. I haven't seen anything consistently to try to get me to do it and I am African American, you know.

*It seems there is always a question about fairness and equality and all that kind of stuff and it has been very interesting to listen to your beliefs and I really appreciate.*

**So I would like to know what did other people say when they talk to you?**

*When I get all done? You would like to know what I found out when I talk with everyone and do a summary?*

**Yeah, I would . I like to read. And then I would like to know what other people are thinking. And then you know I really haven't be like really far in the process to actually know. You know I never had all the tests done and been sitting there and waiting for the transplant, you know. And I understand when you do get on the list they don't just call you when an organ becomes available.**

*That is right.*

*OK..*

*I think you have the opportunity to change your mind..even if you finished your testing and got on the list and waited you would accumulate time. That is why the transplant center is still trying to contact you. You can always say no.*

**I also need money to get some things done that I need to get done when I am on that list.**

*You need money to....to put aside for the costs afterwards?*

**That and also, you know it's like I had went to the dentist and had to have some dental work done. So KDP was paying for some of it, and there were certain processes that they weren't covering. So at my first visit it was like a hundred and some dollars. So the window for KDP to pay for was like 60 days or maybe 90 days. But for me, I am living form government check to government check and I don't have money to put off to the side you know. I'm looking for a part time job in the process so maybe things might change.**

*Don't let them drop you off the process. At some point they might think that you are not interested.*

**I was there at the dentist and they wouldn't do it without the money, and I didn't have the money. Like right now, I don't have the money to get it done.**

**So there are other things too, you know. Like I got a criminal background.**

*So it makes it hard to get a job*

**I can't get a job, so it's crazy. What's the point of sending me through the process of jail or probation and then get out and can't do anything. You know it's how the background coming up. What's the point of serving your time and everything when you don't have the money to get the thing off your record and when you go and try to get a job, you know. What's the point of looking at my background check if you are going to discriminate against me and I can't get a job..I mean....the jobs that I am looking for are cleaning and I can sweep.**

**If I could get a part time job I wouldn't have to count on someone else.**

*Will that eventually come off of your record?*

**You got to pay to get it taken off. It takes money**

*You have to pay?*

**It's call expunged.**

**Each individual thing that is on there you have to pay to get it taken off.**

*So is there a lot to get taken off?*

**Well, yeah, well it's like even if you are charged with something it's still on there.**

**Which is ridiculous. If I am innocent until proven guilty why are the charges keeping me from getting a job. I went to a cleaning service and I never shot or stabbed.**

*So, they weren't violent offenses?*

**Violent offenses don't necessary mean violent. You know like drug charges and stuff are considered violent...certain ones...so it doesn't necessarily have to be violent to be considered a violent crime.**

**It's even to the parole board and everything like that**

*Oh, I don't know anything about that.*

**Yeah, I know. Well, put it like this a felony drug charge..**

*Possession?*

**A Felony, well possession is a misdemeanor..**

**Sales and conspiracy and stuff like that are considered a violent crime.**

*Do they cost more to get expunged?*

**I am not sure. It all costs. I don't think it is more for this kind and that kind. It's like thirty or forty dollars for each one. But I gotta do something about that, and I gotta get a job.**

*It's good to hear that you are so positive about that. You do have a lot to contribute, and you do seem like a really smart guy. We do pay for our past in one way or another.*

**It's not like I wasn't told beforehand that that was going to happen.**

*How old were you?*

**Young**

*And you think you can just get away with it.*

**Yeah, and I am having the same discussions with my daughter right now. And with my son.**

*How old are they?*

**Fourteen and Sixteen. I tell them, you know the decisions you make now they will be with you.**

*Yep, you have got some hurdles there, but I think you have got a really good attitude.*

Tom: Interview 1

*Summarizing the purpose of the study.....What do you think in general about the general topic and what are your thoughts?*

**Well actually, I was quite surprised at the quickness of it because once I told Allison I wanted to get a transplant I think maybe a month later I was doing interviews. The nurse at Hopkins was more informative. She sort of "spoke the language" to**

what I thought, and the doctors tend to talk in circles. She was more informative than they were. And she was nice and I had my grandbaby with me and everybody was happy.

*Oh you did? I bet they enjoyed that (laugh)*

**It was a good experience.**

*Good.*

**In the same token I canceled it two days later because it meant losing.....I haven't worked in twelve years.**

*You canceled what?*

**The transplant because I haven't worked in twelve years and I ain't no spring chicken and it's hard to get work around here. And I pretty much make. I work part time now because my wife is sick.**

*Oh, she is.*

**Yeah, she has degenerative back disease and she has no cartilage in her knees, so she is kind of a little being screwed up. So that is kind of a little battle that I fight at home but it's OK because we've got 20 years together and there's trials and tribulations and right now that is my purpose in life to stay so I can be able to help her.**

*So, did that impact your decision to kind of...*

*Not go*

*Not go forward for transplant?*

**One part of it. The other part is, I don't know, I could be, not mobile at home.**

*So, that was a big part of your decision?*

**That was 80% of it. And then the other factor of mine is finances. The way finances are today, I'm not bad being on dialysis but it's not killing me. I mean I did this to myself.**

*Yeah? What do you mean?*

**I'm an ex addict and ex alcoholic.**

*You mean your kidney failure is directly related to that? To your earlier lifestyle?*

**It was, I know it was. It's not that I am not deserving of one, but there are other people who get it naturally (kidney failure) and I always had the impression that they should get it first. Once I explained that to my wife she was oK with it.**

*Uh hum..*

**And I still feel that way.**

*How did you, um, how did you start out thinking about or when did you first consider transplant?*

**When this place turned from paradise to a hell hole.**

*Explain that.*

**I can't go to another unit because this one is the closest to me with the isolation.**

*Because of the isolation?*

**The only other place that has the iso is further downtown by Hopkins. ....it's is ten minutes from my house. And I mean that is 10 minutes but they don't have an iso.**

**This used to be a really nice facility. Now it's dots and BS and procrastination.**

**They whine about bandaids and needles. "we pay \$13.00 for a needle". I mean**

**small things. Back in the day this facility used to entertain the patients. We used to play bingo.....**

*While you were on dialysis you could do stuff together?*

**We used to do walks. Like the cure for diabetes.**

*There was like a community within the unit.*

**Yeah.**

*What do you think has changed that?*

**The management.**

*Management? Do you mean the management of the unit or the upper management?*

**I can only speak for here. This management changed. The manager that came in- she says one thing and does another. She's all mouth. No action whatsoever, just mouth.**

*Now what role do you think the medical director has in how it is managed?*

**She gave us this schmeel speech one day about not so much profit and gain but how her board wanted cutbacks here. The cutbacks made the techs miserable which trickled down to us. You know that old phrase how shit goes downhill?**

*Yeah, it rolls*

**Some of the really good techs that used to be here left. They were not going to tolerate the BS that this all mouth person.....and if you had any kind of any better education above hers she, it irritated her. She don't want nobody above her.**

*So, are you saying.....she and the physician don't really do much together in terms of working together for the patients?*

**Honestly, I don't' feel it. I mean she spent money to get the building redone; that's fine. She had the building rebuild and that's fine but the quality sucks. I mean, we are not statistics. We are human beings.**

*So, do you feel that patients in general are statistics, or patient on dialysis are?*

**No, we are human beings. If half of these techs had an individual in this condition they would not treat us the way that they do. If they had somebody on dialysis they would understand our emotional state. They wouldn't be like, well, I'll get to you when I get to you.**

*Do you think that is the case in general? That if people don't know what something is like.....*

**How can you empathize? How can you feel something if you never know.**

*I don't know, some people seem to do that better than others.*

**They are assuming. You can't assume on our lives.. These are our lives you are ....with. I am not a game.**

*Well, you know I agree with you because this is the whole reason that this study is based on peoples feelings and experiences. Understanding.*

*So, you said that the social worker referred you to the transplant center?*

**I told Allison, yeah, it's time.**

**Yeah, like two years ago.**

*And you said you did not wait long for an appointment-you already answered that one.*

*Why do you think you got in so quickly?*

**I am going on six years here.**

*Because you had been on dialysis so long?*

**At least that is what I want to think.**

*Now, these are my routine questions and I think you have partly answered some of them. I would like to talk more about your family or your friend. The question is .....involved in your decision to get a kidney transplant?*

**Yes, my wife. She is 93% of every decision I make.**

*She is.....*

**Yeah.**

*So initially she wanted you to try to get the opportunity. Was it just to see what it was?*

**No, I think she wanted it too, but once we sat down and weighed the pros and cons it goes back to finances right now. Like I say I do well...yes I work part time now. I work 9 months. They let me go for three months and then they rehired me. That is how qualified I am.**

*What do you do?*

**I am a retired cook, but right now I clean fish at this market and I..I'm a people person**

*So you like getting out and among people?*

**Yeah, it keeps me from getting housebound.**

*So does your wife get out much?*

**I try to get her to go out**

*Does she need help with getting around?*

**No, not much, not now. A month ago she developed an abscess on her left knee. She already knew that she had no cartilage in that knee. She's like 55 and I wouldn't trade her in for the world but it's like a challenge right now. I just have myself .....and after 20 years I can't kick that to the curb.**

*It's part of the commitment isn't it?*

**She gets frustrated because I guess I'm not as...tender as I should be but I mean I get stressed between work, and also I cook and I clean and I wash. I do it so she doesn't have to and I don't deny her anything, I don't deprive her of anything. You know you need to go out. Take the wheelchair or take the stroller in the car and go out for some fresh air. She's frustrated too because this is not who she is.**

*Yeah, her illness has had a big impact on her...*

**Oh yeah, depression**

*Is there any opportunity for her to get any corrective.....*

**Yes, thank God. Patience and time is prevailing because GBMC is going to finance her surgeries. She goes to Cambridge Hospital, which is**

*I know Cambridge Hospital.*

**She has an appointment with Cambridge, with one of the top docs.**

*It's a great rehab hospital*

**Yeah. She goes there on the 11<sup>th</sup> and I hope I am going to be able to go there with her. It's just when I...I don't want her to see my frustrations because she is hurting. I try to be strong and giddy and uplifting and every now and then we have cross**

**words. Then I tell her it's going to be OK. I love you even though you're broke I need you.**

*Does your grandchild live with you?*

**No**

*Do you have children that live close by?*

**I have a son (my step son) and he has had seizures since he is 6 months old. He's a special needs. I have been with him since grade school.**

*How old is he now?*

**26**

*He's still at home?*

**Yeah**

*He still need help? He still can't live alone?*

**He has moments of brilliance and then he has moments of "duh".**

*Does he still have seizures?*

**Yeah, he has them when he gets..I don't want to say traumatized....If I tell him Brian, I'm going to make you something...and then I don't...Yeah.**

*He get's upset?*

**Yeah. His expectancy level is like ramped up. He mopes and he gets down on himself and he is upset. Yesterday I was going to cut his hair but then I was too tired. You can just see his face go from a glow to being down. ...because he doesn't mean to do a lot of the things he do and I accept his disability but that still don't make it easy. Accepting just means that you... I take the hand that I got and I deal with it but I...**

*You have got a full plate.*

**Yeah, and then coming in here and these jerks...it's not just the techs it's the patients....they whine and complain. Every other day it's a different scenario about somebody and I try not to hear but they's nothing. You can't go anywhere and not get 360 % satisfaction nowhere. So the small things that they squawk about I don't want to hear it. I have my own issues**

*Right*

**And then they all seem to think that Pam is useless.**

*Who is Pam, one of the nurses?*

**The blonde. She is an administrative paperwork nurse. I mean she is not certified and everybody wants to lean on her. Give her a break. Once I find out her status I became OK with that.**

*Yeah. That wasn't her role to be able to treat patients?*

**No, she came in as a part of the administrative staff. But you try to explain to the people that don't want to hear the truth. And they still make juvenile carrying on and unnecessary conversation about that, like she is useless. I am sitting right here and trying to figure out how they became grown-ups. I mean it's not funny but how the hell have you survived this many years not knowing a from b from c? I tell them it's plain as the nose on your face that she is not certified to do that.**

*Well, I guess they need a licensed person in here to oversee things.*

**I tell them she is just administrative and if she can help a patient she will but it's not her job. And then who told you this and I say uh oh. My theory is I can't help you if you don't want to accept. But I will try and I will give you the benefit of the doubt. I will tell you everything I know. It's just nit-picking.**

*Well, everybody must cope differently with dialysis and some people it's part of the taking sides.....*

*Do you mind having to be separated from the group?*

**I like it in here.**

*You like it in here. A little more privacy?*

**And then I like it because yes, it's private and I don't hear the hoopla, I'm here for four hours. And once that 3 hours and 59 minutes is up I am ready to go. And by me no bleeding excessively like some of these patients I want to get out of here five minutes after my machine is off.**

*I bet you do. I bet you do.*

**But then some of these techs will prolong. I don't want to be sitting here 20 minutes after the machine. I explain that to all of them I don't want to be here four hours and 20 minutes, I want to be here four hours and six minutes at the most. Plus I take the bus home. In the winter I take Mobility faithfully. I expect to take the scenic ride home because I live in Parkland. We go this way and then zigzag that way and I get home two hours late and I am frustrated. Like I say I accept that.**

*Let me ask you another question that is more around kidney disease in African Americans and transplant.*

*Some studies have shown that African Amer.....*

**It's not so much of the referral...**

*Well, let me finish....another study shows that AA patients who were referred for a kidn.....what do you think about that*

**I know people...two three, four other people that's black that have gotten a transplant. In fact there is a tech who works up at John Hopkins up in their dialysis unit who got two transplants. He got the first one and he looked good for the first few months but somehow it didn't work after the first six months. He rejected it, so he had to go back on dialysis.**

*Oh..*

**And then there was three people from this unit that got them (kidney transplants) all black. The guy, we called him wild Will, got one and he died from respiratory failure. He got it on a Sunday and on Tuesday he was dead.**

*Oh my gosh,*

*So do you think there is a difference between getting a transplant for African American and whites or do you think that those studies didn't really show what you believe is going on?*

**It's not 65 in one hand and 10 in another. From my eyes it's 50-50. I mean, I only know "excuse my French" on white person who got one but I know of four African Americans who got them. Other than the two people who passed from here, I think it is a possibility that it can work.**

*Everybody is different*

**Right, that is the problem, no two bodies are alike, and chemical reactions can happen.**

*Do you think there can be reasons why someone would start the transplant evaluation and decide they didn't want a transplant once they got through it?*

**Yeah, me. I explained why. Because after I weighed the pros and cons, It wouldn't have been feasible. I don't think that after the transplant I would have been able to go back to the workforce and provide for my family.**

*Tell me a little more about that. About the financial decisions you had to make.*

**Well, three years ago my wife hurt her back.**

*Did she hurt it at work?*

**Yes, and because she only has 15 years' service with Brookville city schools she only got a partial disability. And then when her knees went out, they gave her social Services gave her disability. That's less than \$700. So, we got a car, we got a house, we got food, we got fortunately for us our youngest does work. He has been working for about five years. He makes about \$700. A month plus he gets \$144 from SSI because of his disability. But now, she has well she still has the \$600 she gets from SSI and Baltimore city, but hell, that's just our car payment. I mean, so, my one reason for not maintaining the process is financial; and then I can't be out knowing that my wife is not looked after. The fact that both of us are HIV positive, our families don't know that because they are the hypocritical, foolish people you want to meet. The smile in your face and then turn your back and.... Like I said I was always the black sheep and I got talked about all the time. But talk never hurt me. And I'm gonn, I considered myself a scientist. I experimented....which makes it easy for me to accept.**

*Does it?*

**Yeah, I mean,...**

*You can't change the past.*

**Yeah, and if I could, would I? How much of it would I change? That's my question- but I don't ask myself that question because I deal with the here and now and I'm OK with it. I'm OK with going to work. I'm OK with coming home and making sure my wife get's her shower and things.**

*Yes, you are satisfied with your daily life.*

**Yeah, it's my bump and grind. She gets what she needs. And I want my step son, when he is home, to cater to her more. He has a self-centeredness to him. He will go and get himself something to eat and I will ask him if he asked her if she wanted something to eat and he'll say "no"....and I know he doesn't painfully mean know because he just doesn't have the ...that is who he is.**

*Will she ask for help?*

**Well, now she will.**

*It was hard at first?*

**Yeah, and I didn't understand that. You have a perfectly well to do son in the other room and you won't ask him to go get you something. I would really get indignant with her. He's just watching TV. I didn't want to sound angry when I said it but I**



was forceful about it. She said "no". But you gave him birth, and now it is time for him to pay you back. So, she has progressively gotten better at that.

*I can understand that. Women understand not asking for help better than men.*

If it wasn't for her I wouldn't be willing to not do drugs and not drink.

*So she helped you get clean and take care of yourself.*

And then I got enrolled in a couple of programs and I understand why I did what I did. I had issues with my past...my family. I came from a really large family.

Eleven. I am number ten.

*That is a really large family.*

*How old are you?*

51. And I didn't deal with my issues well but now I do. Now 'get the behind me Satan' and it's OK. I don't let my emotional state rule my physical being. I know it's just a 2.5 second thought that you can just let go. It's when you act on those thoughts that got me in trouble. I don't act on them anymore. I don't have time.

*Do you think that there would be a time when your wife is doing better that you would consider getting a transplant?*

No, because then you are back to going back to work. If when and if, she gets her knees done, she will go back to work. She really likes to work and to be at work.

*Is she your age?*

No, she is 56

Well, she always quoted herself she does not like to be dependent on anyone. She is very independent.

*Independent woman-that is why she does not like to ask for help.*

Sometimes you got to bury the hatchet and wake up and smell the coffee. Right now you are not 360 you are 110. She has hers when she isn't going to eat and she can get mad at me because I will make her eat. She has lost 60 pounds in the last three months. Depression.

I leave at 2:00 and she is still in the bed when I get home. I make her get up and go downstairs. I tell her that if you lay in bed you are going to be physically messed up. You got to change both ways. And I will read scriptures to her. We used to go to a church on York road that we used to go to faithfully but because of her knees she doesn't go anymore. And she is losing touch. And I try to tell her and she doesn't want to hear. But there are days I do get points across to her and she do hear me.

*And she knows you are doing it out of caring for her?*

Yeah, and she knows I love her and wouldn't trade her in. She acts kind of goofy sometimes. It's OK to be sick but it's not OK to be depressed.

*Well...does she have medication for her depression?*

Yes, like I said that new GBMC program is outstanding.

What is that program?

It's at GBMC medical center. They are going to pay for her surgery.

*And does she see a psychiatrist as part of that program?*

Yeah, and she has medicine. Right now it's just a process for her to get into that state. She is making progress.

**Before I go on dialysis I worked six days a week. Sometimes I could come home at 12:00 and get up at 3 and go back to work. My wife says 'how did you do that?' By the grace of God and drugs. And she didn't think that was cute. And now just by the grace of God. I work 10, 11 hours and I come home and I still want to cook dinner and I still want to wash clothes.**

**That keeps me above ground. That keeps me, my sanity level so that I can accept stuff. So.**

*So, she would plan to go back to work? And would getting a transplant mean you would have to go back to work?*

**It would mean I would have to go back to work.**

*Because...?*

**Because assistance would stop**

*Medical assistance?*

**It doesn't make any sense to me. We just barely scratching out a meager living but we are living. We don't have a shed, we don't live in a shack, we got a nice house and we got a car.**

**So, I had no way out and the answer was don't get it. I tell people 'dialysis is not a death sentence, it's a change of life. You should accept that things happen for the best.**

*Well, transplant is a treatment, just like dialysis is a treatment.*

*I think that a lot of times many people don't think through the treatment and*

**I keep hearing what other people say, and I can't go by other people's words. It's not satisfying for me. I need to know myself personally, I need first hand information. If you ask any of these techs, I know what medicine I get; I put my own bandages on, my own tape on. Like I said after four hours, or four hours and five minutes I want to be getting up the hill and going on home. Some of them want to be depended on and they got snotty attitudes. They ain't (excuse my French) they ain't get laid so they cranky... it's not my problem.**

*Unfortunately, yeah it's not your problem but you've got to live through the part that you can't get away from.*

**That's why I say the biggest attribute to myself is acceptance. Accepting the things that I can't change. I work my way through it. It's keeping me clean now going on four years, and I be happy. I mean frustration time is less than a minute. I just say 'look where you've come' and "look what you have to do" and it's gone.**

**But, it get's monotonous, the same routine Monday through Friday. But I like taking care of my wife.**

*So, you are happy with your life?*

**Pretty much, pretty much. It has purpose. And I like the fact that when I cook my steps son asks "Pop-pop what's for dinner?" He likes to eat. WE like to eat.**

*You are lucky because it looks like you keep in pretty good shape.*

**I used to weigh 297 pounds. Ten years ago when they told me I had diabetes I lost 68 pounds in a month. Went on a crack diet.**

*Well, that is not a good way to loose weight*

**No, but ever since then I kept the weight off.**

**And it was through not wanting to take excessive medicine. And I walk. I walk everywhere I go. And it's the new me; I am a lot calmer and a lot of acceptance.**

*You seem a lot happier than a lot of people.*

**That's because, like I said, my first and foremost thing is accepting the fact that this is a life change, it's not a death sentence. And once I accepted that, everything all was set in place. And then my wife got sick and she got depressed.**

**So what can I say, you've got to accept it. My favorite line is 'there is 24 hours in a day. If you have 6 bad ones you're going to have 18 hours of good ones'.**

*Well, the next interview.....*

Tom: Interview 2

*"So, do you want to talk about anything here that you want to change (the transcribed first interview)?"*

**No, from what I read it's pretty accurate.**

*Ok, so um, the last time we talked about your initial experiences with the transplant program, and I was wondering if there's been, in the last month since we have talked, any changes or anything going on in terms of transplant evaluation?*

**No**

*Nothing? You have not heard from anybody?*

**You have to initiate the contact now. They won't call you back. You have to call them.**

*Ok, are you in the process of evaluation or are you on the list?*

**Neither. There is no prospect in it for me. Not right now.**

*OK, so you have not initiated anything and they have not contacted you.*

**No.**

*Have you found it difficult getting in touch with people when you want to?*

**No. They are very punctual, very fast to act.**

*So, the last time that we talked, we talked about whether there was a family member or friend was involved in your decision related to whether or not to pursue a kidney transplant.*

**Yeah**

*And you talked a lot about your family being really important in how you made decisions. Can you just talk a little more about that?*

**Well, it's still my wife basically. No, it's kind of did a 360.....I'm not that happy old person about my family now. She's going through some depression and mental drama, and she is blaming it on me. It's stressing me out; and I would not go through a transplant not thinking she would be by my side.**

**If she's not committed to me....it's just a bummer. I mean our relationship has degraded rapidly and it's very very painful and I don't see no solution in it. I'm done with it. The thought's no longer a thought.**

*You have done a 360*

**Yeah, yeah. Her name doesn't ring bells in my head and when I think about her.....I don't want to think about her. I just don't want to dredge up some old wounds that she just keeps bringing up. It's just a miserable existence right now. So right now in terms of transplant the reason that you did not want to move forward with transplant was that you wanted to be available to help her and everything she is going through.**

**Right.**

*She was very important in terms of your support system and she's just not there right now.*

**What once was is now not important.**

*So it must be really hard to read this*

**No, that's OK because it shows how in time, the situation can change with a blink of an eye. It's just amazing. (long pause) But I don't hold no grudges and I'm still above ground and I still have my health insurance and I'm just going to move on. It's going to be more harder for her because I'm already going through the anguish and pain and mental abuse about it. So it's a new day for me.**

*Are you separated?*

**In the process.**

*And you said you were married for, or you were together for twenty years?*

**Twenty years. Married for ten. I think right after our conversation a conversation came up about I'm overbearing, demanding and disruptive to her health. She wanted me to take charge. She wanted me to do A, B, and C, and when I did it was not to her liking. So.**

*Do you think this is part of something that she is going through with her depression?*

**Oh, I know it is. Yeah. But don't make me feel pain because you're suffering. I'm your...I was your support group. But when you lash out verbally at me, it's worse than kicking me in the groin. Because it lasts longer. The pain will always pick up in my head when she says something. Verbalism kills me worse than something physical. It's like a picture. I can't get rid of it. I mean**

*She was very much your support; I mean in terms of your health. You told me that she was the reason why you had gotten clean and stayed clean and had a purpose for living. That was it at the time, but now it's gone. Now I have to be all of that and some more. I'm not going back out on the street because she hurt me. That would be going back. I'm not going to go forward to go back. That's ludicrous, that's crazy. Uh huh.*

**I have no desire to go back. I'll just have to start over.....get myself back on track and then go from there.**

*I wish you the best. You have a really good perspective on life and I think that should help you.*

**I learned a long time ago you can't let people get in your head because it bothers you more than anything. Like I said, she has.....and now I just got to let it run down (the river) and get it out of my head.**

*So, in terms of her being the focus of your support...it seems silly to talk about transplant with everything else going on, but it is what I am interested in learning about. Um, do*

*you ever see a point where you would reconsider getting your life back together where you would want to get a transplant or is that just too low on your list of what you want to do right now.*

**Right now I would say just 2% of miserableness.....it's great. I have a part time job, I work, I see my grandbaby.....peace of mind. I need myself to have peace of mind before I can parlay or help someone else. Right now I have to do what I have to do. I'm not a quitter.**

*No, you are not a quitter.*

**I just say, 'things happen for a reason'. Another test from God. I know I can pass it. I just have to maintain my self esteem and my dignity. I can't let her indescressions make me go back out in the street. It's not worth it. So. I'm happy. I'm not actually happy, but I'm quite content today.**

*Good*

**I don't house any anger toward her, I just know something's wrong with her. I know she will miss me. That old saying my mother and father used to say 'they will never know until the well runs dry that they miss the well. I'm a strong believer in that. Like when she calls me to say I'm sorry I'm going to say 'it's OK, But you can't keep going this way''. She can't keep monopolizing my time and my heart and my emotions.**

*Yeah*

**The worst part was in her conversation she said that in 10 years I haven't changed. How can you not see a change from a person who did drugs for most of his life until now? How can you not see a change when I bring all my money home to support you? This is why I know that something is wrong with her. And this psychiatrist that she has is not helping her out. I think she's feeding her full of mularky. She comes back worse off than when she left. And I don't want to see her psychiatrist because I would have some choice words for her. And that wouldn't help me either.**

*No*

**Two wrongs don't make a right. I figure that in time she will either get it right, or just move on in the end.**

**I already have a place to move...it's just a matter of days now.**

*Did she ask you to move out?*

**Oh yeah. That was one of the conversations..."I think we should get a legal separation". I said "but you don't have a job", she said "I'm going to be alright", and I said "okey dokey"...I didn't even argue with her. Two days later I was on the phone making the arrangements to move.**

*Oh boy,*

**When I have times like this I watch the news.....there's always somebody worse than me.**

*That is so true.*

**I mean, I am having issues with my life but I'm still above ground, I'm still a nice guy, I still give people the respect that I want back for myself. It happens for a reason...I just can't explain it, and I ain't trying to.**

*Well, you'll do the right thing.*

**I have to. I want to live.**

*Let me ask you some questions...some more specific questions.*

*What are your thoughts about the kidney donor; either the living done who would give a kidney or a deceased person? This is just a general question about kidney donation.*

**I could never show my appreciation for what they did for me if I was to have a transplant. I would be forever grateful and I would want someone to know my appreciation and I would cherish the moment that I got the kidney and be grateful.**  
*Do you think that the way donor organs are distributed in this country is fair to both African Americans and whites equally?*

**Considering I only went for one interview and it seemed to be OK I wouldn't really have an opinion on that.**

*You wouldn't have an opinion on it.*

**No, because I really don't know more about it than my first encounter was good. It was positive and moving forward**

*Do you have any religious or faith-based beliefs that are in conflict with organ donation or organ transplantation?*

**No. Because the body is a vessel and the Lord has made us to do certain things at certain times in our lives. And if being a donor is something that would help someone during our life than God would want that. I mean other than people who burn their bodies with all of their organs intact; that's a waste. But that's their religion. I already know I can't make no donation because of my situation, so. I applaud the people that do.**

*Do you think that getting a transplant is in any way experimental or something that is not proven to be effective; in other words, do you equate transplant with research or experimentation.*

**No, because I know several people with transplants and function fine. I have a customer that comes in and elderly lady that had a transplant 20 years ago. She saw my arm and she said, "Oh, you are a kidney patient". We got to chit chatting. She has had two and I thought, wow!**

(interruption by nurse who wanted to give patient meds in 10 minutes)

*Um, So, the last time we met, we talked about one research study that showed that AA were less likely referred for transplant. Have you had any other thoughts about that?*

**That's not true. You have to make the initial step.**

*Well, it's just one study and that does not mean it's true.*

**From what I have heard and learned if you don't want it you don't apply for it. If you have the initial consult then you get put on a list. And as far as the time frame goes, everything is a waiting game. It has to be the right time, the right circumstances, the right person, you know.**

*So, I think I have asked you all of my specific questions. Is there anything else that I didn't ask you that you would like to talk about?*

**No, now because now my mind is wondering.**

*That is a hard, hard thing.*

**I'm thinking I'm doing the right thing by staying. She just recently had her back done. I was devastated. I really don't understand what part of our 20 years. I have questions like that for her psychiatrist.**

*What about counseling?*

**I asked her about counseling. We were supposed to talk with the pastor of the church.**

*Did you do it?*

**No, it never transpired. This is what she wants. If it was any different she would have put more effort toward it. She is a procrastinator, so I've been through that. Like I told her, I'm not trying to change her but her, she's was going to change me when we got married. A person's going to do what they're going to do. So every time we had an argument that was her line..."Oh, I thought when I married you I was going to change you". She was wrong right there. She knew who I was and what I was about .**

*Do you think that she is waiting for you to make the appointment with the pastor?*

**That ain't going to happen. I couldn't love her in the same regard after the last 30 days of this verbal going on. I couldn't. It would...no. I'm not going to. I am looking forward to leaving. I'm looking forward to getting my feet out on some solid ground. New pavement and look forward. Let bygones be bygones. Nothing lasts forever. You live, you die. Rome was built in 7 days and got destroyed in 2 minutes, you know...things of that nature come to my mind when I think of my relationship with my marriage. It's best to have loved once than never to have loved at all. So, I've loved. Love hurts, that's all.**

*Well, I hope you take care of yourself.*

**I shall. I still love me.**

*That's good.*

**I still love me and I am the most important person that I know.**

*That's good, but you did get a lot of satisfaction out of being there to take care of her. I mean there was a huge value for who you were that came through.*

**And I did it all because I could, and wanted to be different than my father. My father came home, ate, talked trash and hollered at the kids. I'm different and I proved it to myself and to her. It's just not what she wants.**

*How are you going to satisfy that need of yours? Do you have other people that you can..*

**Yeah, me. I'm going to go out and buy the clothes that I want. I mean I dress conservatively. I'm going to make me my highest obligation.**

*Now, back to my original question; if you want to take care of you would getting a kidney look differently to you now?*

**Yes, because I understand you have to have somebody like a care provider.**

*You have to have support.*

**I am going to live with my nephew and he owns his own house and he works and he wouldn't be able to take the time to come to meetings.**

*But maybe at some time in the future?*

**No. It's just not in the cards. Like I say I'm not miserable. I'm quite content and I'm getting the hang of me.**

David: Interview 1

(This participant did not allow taping)

Seven years is too long, I guess you would say so.

I got off to a bad start with the evaluation due to bad information from the program at County General Hospital. They were telling me how high the cost would be after transplant, so they took me off after six years. I didn't even ask for it.

Then I went to Baltimore City Hospital for the evaluation. The records from County General were kind of messed up. I used to send in blood to County General while I was on the list, but no longer.

I got a letter from the County General which I showed to the social worker at dialysis. I got a whole different story when I went to Baltimore City Hospital. County General just kept changing their story and I couldn't get any clear information out of them.

I went to the transplant clinic at Baltimore City and I had to do testing that I had already been through. They sent me to Oceanview for a stress test. I had already had one when my kidneys first failed. So far I have not heard anything more from them in a month.

They did not reschedule me for any testing. I don't know what else is required.

I had to see the cardiologist because I have to have a hernia operation next week. Now the hernia doctor's secretary is making me go and repeat blood work. Don't have transportation if my wife is not available and so I have to pay for transportation. It costs me money every time I have to go somewhere to do more testing. It is taking too damn long.

I would like to throw them (medical professionals) all into a river and let them drown.

I didn't like what they did when my kidneys first went down. They wanted me to take a test about his head because of a stroke I had had in the past, and I had nothing wrong with my head. It's all running me through the ringer. I have to get a cab and pay for a cab.

And it takes up a lot of time.

*Who referred you for your kidney transplant evaluation?*

It was either me or my primary doctor.

No, I didn't have to wait for an appointment but scheduling the rest of the testing was a pain; and they kept rushing me to get it done.

*Is there a family member or friend whom you involved in your decision to be evaluated for a kidney transplant?*

No, there are no family around here. My wife tried to help me.

The stress test nearly killed me.

I don't know if they were full doctors or half doctors or what. They did about 20 MRI's and they kept sending me over to another place to get more testing done. I guess it's OK as long as you have go insurance but it still costs. I felt like I got worked over. They



basically harassed me. I had enough of Snowden Square Hospital. When they finally knew there was not treatment for improving my kidney she didn't know what she was doing.

Other bad experiences at Holy Ghost Hospital when he broke his leg.

Racism is institutionalized in this country; you see it in the banks, the police, the prisons. They been targeting us for years.

They probably do it in the white areas.

Discussed his experience when he was a police officer.

They steal money from social security (? The government does?)

I have always been kind of down on the government. Discussed Albany and the democratic party and how Rockefeller started out the projects (housing projects) which segregated the poor/black population.

Income is one of the big problems.

\$30 million trying to fix it.

Last hired, first fired.

If you have the money you can have all the health care you want.

These medical things are going so high

It's got a lot to do with transportation.

A lot of people just don't get the care because they are worried about putting food on the table.

#### David: Interview 2

(This participant did not permit taping)

*Intro, reviewed previous transcription, asked if there was anything he wanted to talk about further, or anything new since our last meeting; I also inquired about how his hernia surgery went.*

**That personal kind of stuff I don't like to talk about- but this insurance company would send me a new book about their programs...it was Greatna...and I didn't feel like talking because they called me after dialysis and I was tired....so the person said that they would take care of everything. And then come to find out they gave me a program that was worse than the program I was on before. They used to pay the bills, and then I had to pay a part of it. Now they send me the bills and then I have to pay first. CSX has come up with a new program that is a medical savings account. I am tired of Greatna because they don't pay the bills. I have been to court a couple of times because Greatna hasn't paid the bills.**

**I also now have to pay an additional \$200. a month because this doctor comes around and sees me in dialysis once a month. Before I only saw the doctor about once a year. I can barely pay my income tax less yet \$200. (a month) more. Then there is no follow up or anything.**

*What have you found the most difficult with your transplant evaluation?*

**Before when I was at County General, they just gave me all the testing and that was all there was to it. Now (at Baltimore City Hospital) it's up to me and I am**

supposed to go through my primary doctor. My doctor charges me \$35.00 every time she sees me. The lady (at the transplant center) keeps bugging me to get everything done. Can't they schedule some of these things?

*Have you asked them to schedule things for you?*

No, they just keep telling me to go through my Primary Doctor. They want you to do everything on your own.

*Are there any other problems with your transplant evaluation?*

Well, first I talked to the Social Worker who said she'd take care of it. Then they told her something different than they had told me. I think that she had good intentions but what I am hearing now is not correct.

If I go to one appointment a week in addition to my dialysis, I'm all wore out. Whatever they told me, I had to do, and I did it. It's kind of confusing to me. The doctors are not talking to each other.

*Do you have any thoughts on why African Americans are less frequently referred for kidney transplant and.....?*

No. I know that a few rich stars got transplants quickly, but I don't know that there is any difference that that.

*The last time.....family member or friend involved in your decision to pursue a kidney transplant and you indicated that your wife would help with transportation when she could....can you tell me more about that?*

My wife knows about it. My wife does help sometime but she has her own things going on. Her son passed a year and a half ago and she spends time helping out with her grandson. She also spends time helping her family...her brother. He is the last one left in the family. Then there's the church stuff like choir practice. She is really busy with these things. She will come and get me if I ask her, but you have to put your bid in for her time because she is busy.

*Exploring beliefs about transplantation.....*

Yeah, I still want it (a transplant). I hope they don't get me eliminated (because I don't have my testing done)

*Still want a transplant or worried about cared during the transplant or the care after he receives a transplant.*

It ain't that I'm uncooperative, but sometimes I miss some medications. A lot of things are confusing.

*Is there someone who can help you with these things and with organizing your care after transplant?*

No friends. My daughter is busy working and stuff.

*Thoughts about the kidney donor (Living or deceased)*

Well, they talked to me about taking kind of a second hand kidney but I kind of preferred a younger person. They were rushing me when they talked about the types of donors. At first I didn't want no cadaver but I thought that meant that the person had been dead a long time before they took the kidney.

*Fairness about how organs are distributed...*

**I wouldn't really know. But I know that in general there is so much corruption everywhere. I rarely put trust into things.**

*Faith issues with transplant?*

**No**

*Equate transplant with research?*

**No, well.....I know of one transplant that didn't work, and I know of one that was a success....(dialysis nurse interrupts here to remind him that she donated a kidney to her daughter).....two that were a success .**

*Anything else he wants to talk about?*

**I need to get taxi service or MTA to get me places and you have to wait and wait to get picked up.**

Pam: Interview 1

*The reason I am doing this study is to.....*

*'you can't fall asleep on my hun, is it OK if I keep waking you?'*

**Oh, say that again, I didn't hear**

*Initial question repeated....I want to know what your thoughts and beliefs are about getting a kidney transplant.*

**I feel good about a transplant, yeah.**

*You feel good about it?*

**Yeah, uh huh. I feel good about it.**

*Did you have the evaluation?*

**I had it, yeah.**

*Ok, so I want you to tell me what you believe, not what you think I want to hear, OK?*

*There are no right answers to these questions.*

**Uh huh**

*When did you first consider a transplant?*

*When did you first think about getting a transplant?*

**Um, when I first started coming here to dialysis**

*And who referred you to the transplant center?*

**I forgot**

*Was it one of the nurses here? Did you just refer yourself? Was it a doctor?*

**A doctor, it was a doctor.**

*Did you have to wait a long time for an appointment?*

**No**

*Was there a family member or a friend.....involved in your decision.....*

**My son, I involved him. My son.**

*Can you tell me a little bit more about that?*

**I ask him would he go for a physical. I wanted him to have a physical and all that to see how healthy he was and to see how his kidneys were doing. But he never did make a step**

*Did he encourage you? Did your son encourage you to go for the transplant evaluation?*

**No**

*He didn't encourage you?*

*Why did you want him to go and get a physical?*

**Because they said that he needed to be checked out first to see how he is doing.**

*First before what; to make sure that he did not have kidney disease?*

**To make sure he didn't have it himself.**

*Ok,*

**But he never made that move; he never made it**

*So he didn't get his kidneys checked out?*

**No,**

*Do you remember what it was like to meet with the transplant team?*

*Do you remember what the evaluation meeting was like?*

**Yeah, I went to the evaluation and they had told me, they had told me, you know that I had to lose weight.**

*They told you you had to lose weight?*

**Yeah, fifty pounds**

*Fifty pounds?*

*What else was it like? What else do you remember about the meeting?*

*Did you see many people?*

**A few people, yeah, a few people.**

*Ok, and what are your thoughts about having to lose fifty pounds?*

**I told them it was so hard for me to lose it and they said well, you got to try to lose it.**

**I have got to at least try to lose it.**

*Uh huh.*

**If I want a transplant I have to try.**

*Have you made progress with that?*

**Not yet. I got to though.**

*Did you understand why you have to lose the weight? Did they make that clear to you?*

**Because I am too fat.**

*Why does that matter?*

**Because I'm overweight, I guess. Because I am overweight.**

*And would that cause a problem?*

**That is what they said.**

*How did you feel like you were treated?*

**They talked to me real nice.**

*They talked to you really nice?*

**Um hum.**

*That's good. Were there any concerns that you felt you couldn't talk to them about?*

*Was losing weight something you were able to tell them you were worried about being able to do?*

**Yeah**

*Some studies have shown that African Americans as compared to whites.....do you have any thoughts about this?*

**No**

*So, do you have any thoughts about anything that I have not asked you about?*

*Do you have any concerns about transplant or do you have a coordinator you can talk to?*

**Yeah, I have a coordinator.**

*Do you have her number if you have any questions?*

**I don't have her number.**

*So, how would you get ahold of her if you needed to ask a question?*

**I don't know. I don't know if I can get in contact with her now.**

*Probably the best thing would be to ask somebody here at the dialysis unit because they have the numbers and they can help you.*

**Alright.**

*And what about losing weight? What are you going to do about that?*

**I got to lose it; so that's what I got to work on.**

*Maybe talk to the dietician here?*

**Yeah, talk to her.**

*Do you know what your goal weight is?*

**So they said to lost fifty pounds, that's what they told me.**

*What did you weigh when they said to lose fifty pounds?*

**Two ninety**

*So they want you about two forty. OK, well good luck with that. I will come back the next time.....*

Pam: Interview 2

*The last time we talked you, we talked about the study to see what your experiences are; and that there are no right or wrong answers.....them telling you that you needed to lose weight..*

**Right**

*Fifty pounds, and that was going to be hard.*

**Fifty pounds, right, hard.**

*Pause.....and we had talked a little bit about your son.....getting his kidneys checked out. Did he do that?*

**No**

*He never did that.....so, were they looking at him to maybe be a donor for you?*

**Yeah, I think they were.**

*Ok, so that makes more sense to me now. Um...so, um, has anything changed over the last month since I was here about your transplant evaluation?*

**Huh Um, not about the transplant evaluation.**

*Nothing changed? (I had been told by the dialysis doctor that she had received a letter saying she was being removed from evaluation because she had not lost the weight and she had not completed her workup, but it seems she did not know this or did not want to talk about it.)*

**Uh Um.**

*Nothing, OK.....so what's happening at this point?*

**Nothing, I just want to get on the donor list for a kidney.**

*You are going to get on a donor list for a kidney? So nothing's changed? Have you talked to anyone from transplant or done any more testing?*

**No**

*Have you been watching your weight maybe?*

**Yeah, I've got to watch my weight, watch my weight uh huh.**

*Have you had any thought about having someone to help you with the transplant evaluation?*

**Yeah.**

*A family member or friend to help you get through the process?*

**Yeah, a friend or a family to help me, yeah.**

*Do you have somebody in mind or have you asked for help?*

**I didn't ask for help, uh uh.**

*You didn't ask for help?*

**Uh uh**

*So, what do you think you need to do to get on the list?*

**I guess you've got to follow the instructions and stuff.**

*Do you know what testing you still need to do?*

**No, I did all of my testing.**

*You did all of your testing. So you are just trying to lose the weight...?*

**Uh huh.**

*You talked before about not knowing how to contact your transplant coordinator.*

**Uh huh.**

*Did you figure out how to get in touch with your transplant coordinator?*

**No, uh huh.**

*What would you do if you needed to get in touch with your coordinator.....ask a question.....?*

**Like I say I'm running out of places, running out of places. And the only choice there is is to get a transplant.**

*Running out of places for dialysis?*

**Uh huh.**

*Did you talk to the dietician about helping you with your weight loss?*

**Uh huh, NO, I haven't talked to her yet.**

*Have you received any letters from the transplant center in the last month about what to do?*

**No**

*Thoughts about the kidney donor.....?*

**Uh, actually about somebody give their kidney up? No, uh huh.**

*Fair organ distribution?(Do you think it is fair to AA and whites equally?)*

**Yeah.**

*Religious or faithbased.....in conflict with organ donation or txp?*

**No**

*Experiment? (equate transplant with experimentation)*

**Uh huh**

*Yes, you do?*

**Yeah**

*What part of it do you think has to do with research or experimentation?*

**Well (silence) um**

*Just the whole thing?*

**Yeah, the whole thing.**

*So, how does that make you feel if you want a transplant and you think it's kind of experimental?*

**Silence.....Yeah, experiment, yeah. Oh I'm cold.**

*Are you cold?*

*Is there anything else you want to talk about? Thoughts or concerns?*

**No, Oh I'm cold.**

*Thanks and departure.*

Shirley: Interview 1

*The reason I am doing this study.....*

*You told me you were evaluated for a transplant. When did you first consider a transplant?*

**Uhm...this year**

*This year? And you had been on dialysis already for eight years? (Patient nodded quietly)What made you start thinking about it at this point?*

**I took sick real bad**

*You took sick real bad? And did somebody bring it up to you?*

**Um hum**

*Tell me about your sickness*

**It was just.... you get tired of being sick.**

*Have you been sick a lot on dialysis?*

**Uh huh**

*Were you in the hospital? (patient nodded quietly). So, did somebody suggest that you get a transplant?*

**I am just tired. I am just tired of this.**

*Tired of this?*

**Um hum. You can't, you can't really do things that you want to and you get tired. Sometimes I get tired real fast. You have to watch what you eat, and sometime I want to eat everything.**

*So, it is the lifestyle with dialysis and not being able to eat what you want and getting sick a lot?*

**Yes.**

*So, do you know who referred you for your transplant?*

**No one.**

*Did you just call up yourself?*

**Yes.**

*How did you know where to call?*

**I asked.**

*Did you ask here (dialysis) or did you ask your doctor?*

**I asked here.**

*So they sent your name to the transplant center, and then you were contacted?*

**(Patient nodded quietly)**

*Did you have to wait a long time for an appointment?*

**No**

*Was there a family member or a friend whom you involved in your decision to go for a transplant evaluation?*

**Family.**

*Family? Can you tell me a little more about that?*

**I have children, and they say they would all give me a kidney because I love seeing my grandchildren.**

*I imagine they want you around too.*

**(patient smiled and nodded)**

*So they encouraged you?*

**Yes.**

*Tell me about your children. How many do you have?*

**I have seven**

*Seven children! Do they all live close to you?*

**Um hum.**

*That is wonderful!*

**(patient smiled)**

*So, do you live with your children?*

**No, I have, um three with me. One of the three is just temporary.**

*Uh huh. So you do have some of them with you.*

**And I just can't be alone. They are scared for me to be alone.**

*It can be hard to be alone, and it's nice that they can be with you.*

*So, tell me how they supported you in the decision. Did they go with you to the appointment?*

**I went to the appointment by myself. It's just I'm tired of..... And you can't.....work and go places. And I can't really go places (5.30)**

*Do you have grandchildren?*

**Yes, and I just found out that I may have another one on the way.**

*Oh, congratulations! That's a wonderful part of life-grandchildren. I have some grandchildren too.*

**You have? How many do you have?**

*I have four. How many do you have?*

**Twelve.**

**And then I want to work. I want to go to work.**

*You want to go to work? What kind of work do you want to do?*

**I like clerical work, or um, just talking with people. Going to the senior citizen's home or something.**

*Do you like working with the elderly?*



**I like keeping someone company and doing something like that.**

*Uh huh. So, you would like to get a transplant so you can get back to a more normal life so you can go to work and help people?*

**Uh huh, and be with the grandchildren more.**

*You are still young and have plenty of life left to be able to do those things.*

*That is a nice goal, a very nice goal.*

*What was it like when you met with the transplant team?*

**Friendly**

*Friendly? Did they answer all of your questions?*

**It was kind of overwhelming, but they answered my questions.**

*And how did you feel like you were treated during the experience?*

**I was treated well.**

*What is happening with your evaluation now?*

**I haven't heard anything. I don't know. There is so much going on. When you've got children and then you come in here, once you get home you are drained and you get "ma this, and ma I need this, Ma you need to go with me here....you know, you just...**

*You don't focus on yourself?*

**(quiet nod from patient, no comment)**

*So, you are not sure what the next step is? Do you know who to call to find out?*

**No, I don't.**

*You don't know? Well, I could help you find out that. Because I do know that there is usually a lot of testing that you need to do and if you need help you need to ask for help. And I will give you the name of a person to call. I know what you mean about getting home and there are so many things to do that you don't get to do what you need for yourself.*

**Um hum.**

*That (the testing) might be something that your children can help you with if you tell them "I need you to help me with this".*

**Oh I tell them (laughs)**

*Do they help to take you to appointments and things like that or do you use transportation?*

**I normally go by myself.**

**I normally go by myself because they have their own lifestyle. They busy with their own family.**

*Um, so is there anything about the evaluation that I didn't ask you about that you want to talk about?*

**No, not right now.**

*Some studies have shown that African Americans as compared to whites.....or know this to be true?*

**No.**

*Do you know that African Americans have more kidney disease?*

**Well, you can look around and see.**

**I was told that my kidney disease came from medication.**

*Do you know what kind of medication?*

**Zestril. I was on it too long.**

*Do you think there is any fairness issue....*

**I can't answer that.**

*Ok, that is a fair answer. These are the kind of questions I will go over again the next time we meet.....*

**Ok,**

## Shirley: Interview 2

*Intro.....you had talked about not being quite sure who your coordinator was.....and you were kind of overwhelmed when you got home (helping family).....would like to go back to work.....helps me understand your goals. (discussing testing needed to be done) Will you be scheduling the heart testing or will your doctor.*

**The doctor because I forgot where I was supposed to go.**

*Are there things that you need to have done in terms of testing that you found hard to get done?*

**All of it.**

*What has been hard about it?*

**Remembering what has to get done.**

*Do you think if you had a list it would help you keep track better? Did you lose this letter when it came (evaluation letter)?*

**It probably came around Christmas time or something.....**

*This came in October.*

**Well, my daughter was still living there and it probably got misplaced.**

*OK, well you need a special place for your mail. Maybe you could have a special place for your transplant mail because if you don't follow up they think you are not interested.....*

*Can you try to call your coordinator once a week when you get home from dialysis and say "what do I need to do?" It's a squeaky wheel like of system.*

*So, do you have any thoughts about why there may be a difference between African American's and whites in terms of getting on the list?*

**I would like to know. (then she felt some pain in her arm and talked about that)**

*Long pause.....tell me more about how you think your family could help you get your transplant*

**They say they want to know what they got to do so they can help. My daughter is now pregnant so she won't be able to help me. She is in her early months now. She would probably go with me.**

*If you want them to call your coordinator to ask about finishing your testing, they can call for you.*

**Ok**

*What are your thoughts about getting a kidney?*

**My thoughts about getting a kidney? I hope everything works out.**

*Why do you say that?*

**I know some people that they tried and it didn't work out for them.**

*Do you have any concern about your care during or after the transplant?*

**Yes. I really don't have no-one to be there with me and I don't have nobody to help me take my medicine. My son is looking for work and sometime he just leave out. And I probably could stay with my daughter but I don't really want to be a burden to nobody.**

*Well, you take medicine now. Are you pretty good about taking it and do you have a system.*

**After I leave here I go home and get me something to eat then I take all of my medicines. Before I know I need to take.**

**Someone said I have to take about fifteen pills for the rest of my life (after transplant)**  
*They start out as a lot but then they decrease over time. The first few weeks it is important to get the right dose for you and you will have your dose changed based on your blood tests.*

*(nurse further discusses post transplant care)*

*Do you have any concerns about the surgery?*

**Is it a long process?**

*The surgery itself is about 3 ½ hours and you are usually in the hospital about a week. But the biggest part is learning to take the medicines and learning about your body.*

**Do you start urinating?**

*Yes (discussion)*

*What are your thoughts about the kidney donor?*

**I just hope that whatever one I get is a healthy kidney. I don't want to have to go through another transplant. I hope it's a female donor.**

*Do you think that the way organs are distributed is fair to African Americans and whites equally?*

**I don't think it's fair.**

*You don't think it's fair?*

**It could be the insurance.**

**If a person is more anxious or ambitious**

*You think that person will get it first?*

**Uh huh.**

*Do you think that has to do with race?*

**No**

*Do you have any religious or faith based beliefs that are in conflict with organ donation or organ transplant?*

**No**

*Do you think that getting a transplant is in any way an experiment.....*

**Sometime I think that.**

*Tell me more about that.*

**Sometimes I think that they just want to experiment on you.**

*Can you tell me more about that.*

**Just stuff that you hear when you grow up.**

*What do you think about that?*

**It makes you wonder, is it true?**

*Does that frighten you?*

**Uh huh. Cause you wonder since I'm going through transplant...you wonder.**

Evelyn: Interview 1

*Intro: "the reason I am doing this study.....If we can talk about your experience, Ms.Good. When did you first consider a transplant?"*

**About, about a year and a half ago.**

*About a year and a half ago?*

**Yes.**

*And you had been on dialysis already for how long?*

**Ten or eleven years.**

*Who referred you to the transplant center?*

**Hesitated.....A lady came around and asked me questions.**

*Was it somebody here in the dialysis center?*

**No, I think it was somebody from outside.**

*Someone from outside the dialysis center but they came in here to talk with you?*

**Yeah, they was working with the transplant center. It was Beth I think.**

*It was Beth from the transplant center?*

**Yeah,**

*Did you have to wait long for an appointment?*

**No.**

*Was there a family member or a friend whom you involved in your decision to be evaluated for a transplant?*

**Yes.**

*Can you tell me a little bit about that?*

**Oh, my daughter. I talked to them about it. Most the family has kidney problems.**

**So when I asked them about donating, then they had problems too. So, I was evaluated and got the treatments done so I could be evaluated and be on the list.**

*And how did your daughters help you?*

**They takes me to the appointment that I have to go. You know, it was my decision.**

*It was your decision.*

**Um hum.**

*Do you live with one of your daughters?*

**No, I live with my son and his wife and grandchild.**

*And are they helpful or is it mostly the girls?*

**They are helpful. If I need to go to an appointment or something, they are always there. They help me.**

*That is very nice.*

**Um hum.**

*What was it like to meet with the transplant team the first time you met with them?*

**It was like we did a lot of talking and explaining, you know. It might be a long wait, and I might get one. It depends how you feel, my being up in age. I might, you know, not want it. If there was one that, you know, didn't have kidney disease, you know, I might be able to get that kidney.**

*And how old are you?*

**Seventy three**

*So um, did you get a lot of information at the appointment?*

**Yes, yes. They told me it might be a long wait. And they told me about the appointments and the things, you know, I will have to do.**

*Yes*

**And about the treatments I would have to go through, so forth like that.**

*And, how would you describe that process?*

**Oh, it's a long process, a lot of doctor appointments and stuff.**

*It is a very long process.*

**Well, they told me at one of the appointments that it would be a long time.**

*How did you feel you were treated when you were there, learning about the evaluation process?*

**I thought I was treated fairly.**

*You thought you were treated fairly. Did they take enough time with you?*

**Yes.**

*Did you have somebody come with you to the appointment?*

**No.**

*Were there any questions or concerns that you didn't feel you could talk about there?*

**No**

*What are the next steps for getting you to be on the list?*

**I have one more appointment for the 8<sup>th</sup>. It's a walk-in appointment. They said then I might be finished.**

*You might be finished?*

**(smiling) I hope.**

*Is there anything about getting the appointments scheduled or done that you want to talk about. Transportation?*

**No, I didn't have no problem. Like I said, my son, my daughter and my granddaughter was there if I got an appointment somewhere. They see that I make the appointment.**

*Some studies have shown that African Americans as compared to whites.....*

**I've heard that before, yes. I've heard that blacks especially have problems to get a transplant.**

*Why do you think that is?*

**I don't know.**

*Well, there is no right answer, but I think a lot of people would like to know if there is an answer to that.*

*In your experience do you think that things have been fair and that you have been treated fairly?*

**Yes, so far what I have gone through with it, I think I have been treated fair.**

*Good. Do you have a primary care doctor? Is that somebody who helps you schedule these appointments?*

**Yes, he helps me with some and Beth, at the transplant center, she helps me make some of the appointments?**

*Is Beth your transplant coordinator?*

**Yeah**

*Are you able to get in touch with her when you need to?*

**Yes. If I call and she don't answer she leave a recording and she will call me back.**

*Ok, so is there anything that I didn't ask you today that you want to tell me at this point?*

**No, I'm not too much of a talker, but I listens and I can answer.**

*You have done dialysis for a long time. Transplant would be a change in your life, wouldn't it?*

**Yes, it sure would.**

Evelyn: Interview 2

*My intro and review of the transcribed interview #1 .....You know your coordinator and know what is going on. Is there anything more here that you want to tell me?*

**No, that's about it.**

*The last time we met we talked about whether or not there was a family member or a friend that was involved in your decision to pursue transplant and you told me that your daughter particularly was the person and that you talked with her about kidney transplant, and that your family mostly had kidney disease...*

**Mostly, yeah.**

*Most of them do?*

**Yes.**

*Did they already know or did they find out that they had kidney disease when they wanted to be a donor?*

**The, uh went, you know, they had doctor appointments and they was told. They already knew by the time I was starting (my evaluation).**

*And you have two daughters, right. Do they help you with appointments and things like that.*

**Well, I have one daughter that is able to help me, and the other daughter is partially blind.**

*And your one daughter is able to drive you to appointments?*

**Yes, my daughter and my son, and grandchildren.**

*So all of them do help you.*

**Yeah**

*Do they help you to make decisions about the treatment that you need or .....*

**Well, we all talk about it but basically they let me make, you know, my own decision. So if I feel that I'm able to do something, or whatever, they go along with my decision.**

*Now that you know all about the process...are you finished with your evaluation Ms. Good?*

**Yes.**

*Are you on the waiting list?*

**Yes.**

*And um, what are your thoughts now.....do you have any concerns about your care during the transplant or after the transplant?*

**Well, like I said, my family is still there for me and can help with the care that I need.**

*What about being in the hospital?*

**Well, they be there for me as much as they can.**

*And when you come home.....*

**They be there, yeah.**

*Do you feel prepared in terms of knowing what will happen?*

**Yes**

*What are your thoughts about the kidney donor?*

**Really I hadn't thought. But it's very sad that there is someone with better health than I have that they pass, and I may have one.**

*And there are people with good kidney who die and want to donate. Since donation is being talked about more, there are more people donating.*

*Do you have any thoughts about kidney donation or beliefs that you have ?*

**I wouldn't want one that is sick, you know, but if they are in good health...pause..kidney was good, you know.**

*Do you think that the way donated organs are distributed is fair to African Americans and Caucasians equally?*

**I'm not going to say. You know, I don't know that much about it to say more whites get it than blacks because I just started in the program last year. I see quite a few blacks get kidneys and I see quite a few whites get kidneys. So, I won't say. I be more...**

*Do you have any religious or faith-based beliefs that are in conflict with organ donation or organ transplant?*

**No.**

*Do you think that getting a transplant is in any way an experiment .....?*

**No, I think it's good and it has been researched to be good.**

Jennifer: Interview 1

*Intro.....what do you think about that?*

**That's great.**

*When did you first consider a transplant?*

**Well, they talked to me about it last year and they were saying that with me having diabetes and stuff with complications that it would be hard to be on the waiting list, to see if anybody in the family is compatible to be able to donate me a kidney. And my son and daughter, they were trying to go through with it.**

*Who is "they"?*

**The nurse here at dialysis**

*So she brought up the option to you.*

**Yes.**

*Was that Lisa?*

**Um hum**

*And did she actually refer you or did she give you the number and have you call?*

**The social worker, I think she called for me. Kate. She set everything up.**

*Great. Um, did you have to wait a long time for an appointment?*

**For dialysis?**

*No, for a transplant appointment.*

**Oh no.**

*Was there a family member or a friend whom you involved in your decision to be evaluated for a kidney transplant?*

**I talk to my son and daughter. Well, I let them know that at the time, my kidneys was bad and I need a transplant. And right then they hopped right on it "Mama I'll try, I'll try for you" cause I explained to them that it would be hard for me, as far as the list, and that I'll probably won't be very successful in getting a transplant right away.**

*So they said we want to be tested.*

**And I got the number but my son lost it.**

*I can give you the number before we go. So what was it like when you went to meet with the transplant team?*

**It was very exciting. I went by myself and then afterward I couldn't remember everybody's names and what department. But it was alright. It was exciting.**

*It can be very overwhelming for some people, I think.*

*So how did you feel you were treated and how did you feel about the experience?*

**I was treated fine. I was treated the best. I think I was treated the best they could treat anybody.**

**Very polite, and they wanted to make sure I could understand what they were talking about.**

*Did you come away understanding pretty well?*

**Yes.**

*Were there any questions or concerns that you did not feel like you could ask them or that you did not feel you could talk about?*

**Oh no. It was very complete.**

*How about since then, um have you been able to get in touch with them or have you had questions?*

**I haven't talked to them since the first time. One time I was supposed to have all these tests done and I didn't finish. My doctor changed. And that's why it was so**



long, so they took me out. But Kim set it up (or was it Lisa). Kate was the one that got me Dr. Frank and um, got it started all over again and it was like three weeks at the most and I got everything done with this new doctor. And I asked him if he could be my primary doctor and he said yes.

Well it was taking me about seven or eight months with the other doctor.....

*So, do you know what else you need to do or are you finished?*

**I got one more test and that's my pap smear.**

*Tell me about getting to the appointments that you need to have. Is that hard for you?*

With mobility, sometimes they come and they tell a fib that they'd been there and they never came. And then it's hard for me because I've got no way of getting to where I need to go.

*How far ahead do you have to schedule Mobility?*

**Ok, like for my dialysis I have to do it seven days before. But for one day, Like today I can schedule for tomorrow, or a couple of days before.**

*What would you say is the hardest thing getting through all of those tests?*

**Hard?**

**Nothing**

*Are you pretty organized?*

**Yes**

*Have you contacted the transplant office or called them about anything?*

**No**

*Have they called you?*

**No**

*So you are just assuming everything is ok.*

**Everything is OK. Now usually if I have a problem or something I talk to Lia and Lia hops right on it. Say like I wanted to call the transplant coordinator I would tell her and she would call and tell the transplant coordinator I want to talk to her and give her the number. They are great here.**

*That's wonderful*

**I could tell Lisa or Kate anything and they hop right on it. 'Cause I was telling Lisa the problem I was having getting a doctor and she said 'do you want me to help you get a doctor?' " and I said "yes" and the next time she had it all scheduled for me. That's Doctor Frank, the one that helped me get all my tests done.**

*Some studies have shown .....African Americans less likely to complete the evaluation.*

*Have you ever heard this or do you know this to be true?*

**I haven't heard that. (referring to unit staff) They are so much like my family.**

*After transplant some people miss their dialysis 'family'.*

*Do you think that there is anything that makes African American's less able to complete things?*

**No**

*Question about if it's fair for African Americans.....*

**Yes, it's very fair.**

*The next time when I come back....*

Jennifer: Interview 2

*Have there been any changes in the last month in terms of your transplant evaluation, being contacted by the transplant center or trying to contact the transplant center?*

*Q13*

**Yeah, they contact me all the time about the stuff that I still need to get done, to finish the process. So, they pretty much do that.**

*They contact you?*

**The decision I made myself not to go through with it at this time.**

*So, did you tell them that?*

**Well, no not really because they keep trying to get me to finish regardless. They are pretty persistent and they call a lot to remind me of what I need to finish in terms of testing. Especially with me being young and stuff.**

*So they contact you to try to get you finish up the testing?*

**And they also call my social worker, and she will come and talk to me about it. And they send stuff in the mail too.**

*So have you decided to stop the process, but you haven't really told them?*

**Yeah, well before, you know, this is my second time, you know, but once you don't do the things you need to do over a certain amount of time they stop contacting you. One of the techs here will talk with patients and try to encourage them, you know, about the process, and the social worker does as well.**

*So you are still going along with it but you are personally still feeling it is not for you?*

**Well, in the beginning, you know, I had some thoughts about it, then I changed my mind, and then I thought about it again. It's like the time, me trying, and it's like for me there's no family.**

*Yeah.*

**Well, you know they tell you 'you need to do that because it's the thing to do'. You know what I'm saying. And some of the people here it's 'so on and so on'.**

*The last time we talked we talked about whether a friend or family member was involved in your decision to pursue a kidney transplant. And you really talked about that a lot as being one reason why you didn't want to move forward because you really didn't have the support...*

**Oh, the support, well basically that was about, you know, financially. I'm saying you really need financial support in terms of that. But um,**

*So it's more financial support?*

**With me, yeah, and you know I, um I mean I would need the financial support from somewhere until I'm back and able to work and help with getting the medications. When it comes to the point when the benefit is not paying for that anymore I would need that support.**

*What about the people support? Can you tell me about the people in your life that might help you; You know anybody that you think is important to you to make important life decisions...*

*Q!5*

**Um, well I don't really have any people like that in my family- it's not really close knit. So, you know everybody is basically doing their own thing, you know. And um, that's pretty much it**

*So you don't talk to somebody about this decision.*

**Yeah, like maybe a friend or a girlfriend or something like that, Yeah, it's mostly like friends in general.**

*So, you are closer to your friends?*

**Yeah, well that's normally how it goes when you don't have a close knit family.**

*That is true, that is right.*

**You meet nice people and they are good friends and you try to keep them in your circle.**

*So do you have a girlfriend now?*

**Yeah.**

*Do you have a pretty close network of friends?*

**Yeah, a few of them. There's a few friends.**

*So do you talk to your girlfriend about your illness at all?*

**Yeah, I was dealing with her from even before I had the situation.**

*So have you been together for a while?*

**Yeah, off and on. So she pretty much knows what is going on.**

*Um, so I guess my next question is now that you have learned more about the transplant process, what your thoughts about getting a kidney...and I guess your thoughts are still that it's not for you right now?*

**Q16**

**It's not really that, it's that um, things come up along the way. You know like I said that you need that financial support. Even when you think everything is cool and going to be OK, there are still things that come up along the way that you are going to need money.**

*Money is tight*

**Well my decision wasn't all the way made, you know I was going through it...I was going through it but I got at one point where if there was a financial situation that I couldn't take care of and I really don't know nobody that I could go to, you know. I got this girlfriend but she is struggling too, you know she is a single parent so she is struggling and I am struggling and I really don't have people that I can just call up when I have a need like that.**

*I understand. I think some people think that the transplant is a quick fix and it will fix everything but you seem to have a pretty deep understanding of the responsibilities. How do you think you got that? By going through the process and talking to people or what?*

**No, that's just the kind of person I am. I try to think things out before I make decisions. It's not jump into things.**

*What are your thoughts about the kidney donor?*

**Q17**

**What's my thoughts about the donor? I think it's a good thing...I'm a donor myself. Even though I might not get a transplant if I can help somebody else who**

might want to go down that road, then why not. I mean I'm here I'm not going to need the organs.

**You talking about the living donor?**

*No, I am talking about either...a living donor or a deceased donor.*

**It's a good thing that people do that. If you can help somebody out then why not?**

*Have you ever know somebody who got a kidney from a friend or a family member?*

**No, or if they did I don't know that. People that I have met after the fact that was on dialysis and got transplanted I don't really know where their donor came from.**

*Do you think that the way donor organs is distributed is fair for African Americans and whites equally?*

**Q18**

**Um, I really don't know. That's a hard question to answer unless you know how many organs are coming in and where they're going and who is getting them.**

**That's kind of hard to answer. But I see people get transplants, you know here in my clinic, and they're all black people in here, so.. but the rate towards the predominately white clinic and whether or not they are having family donate, I don't know.**

*Do you have any religious or faith-based beliefs that are in conflict with organ donation or organ transplant?*

**Q19**

**Well, not really religious, just beliefs of my own. I am a strong believer that when it's your time to go you are going to go transplant or not, you know, I am just a believer that when your number is called you are going to go.**

*So you don't see any conflicts with your beliefs and transplant?*

**No, not me.**

*Do you think that getting a transplant is in any way an experiment.....*

**Q20**

**NO, I don't. I don't have no reason to believe that.**

*Is there anything that I did not ask you about organ transplant or organ donation that you want to add?*

**Not right now. Nothing on the top of my mind.**

*Um, (pause) OK,*

*Would you have any concerns about your care if you were to receive a transplant....after receiving a transplant?*

**No, they told me that for a while you have to have somebody with you to make sure you recover and I don't have any problems with that.**

*Those are all of my standard questions. Did I not ask you something?*

**Well, if something comes in my mind I will let you know when you call me (to go over the transcription).**

*What's a good time to call you?*

**Well, anytime is good. You have got my home number. If I am not there just leave a message and I will get back with you. I'm pretty much home a lot.**

*OK, so there is not anything I didn't ask you that you want to talk about transplant or donation or anything?*

Q21

No because in the beginning I was thinking of something else when you asked me about it which I pretty much covered in here. WE covered the first time. So this time we got to what it's really about, like do I think there is any, um setbacks. Not setbacks but things different for African Americans trying to get a transplant. I haven't seen anything consistently to try to get me to do it and I am African American, you know.

*It seems there is always a question about fairness and equality and all that kind of stuff and it has been very interesting to listen to your beliefs and I really appreciate.*

**So I would like to know what did other people say when they talk to you?**

*When I get all done? You would like to know what I found out when I talk with everyone and do a summary?*

Yeah, I would . I like to read. And then I would like to know what other people are thinking. And then you know I really haven't be like really far in the process to actually know. You know I never had all the tests done and been sitting there and waiting for the transplant, you know. And I understand when you do get on the list they don't just call you when an organ becomes available.

*That is right.*

OK..

*I think you have the opportunity to change your mind..even if you finished your testing and got on the list and waited you would accumulate time. That is why the transplant center is still trying to contact you. You can always say no.*

**I also need money to get some things done that I need to get done when I am on that list.**

*You need money to....to put aside for the costs afterwards?*

That and also, you know it's like I had went to the dentist and had to have some dental work done. So KDP was paying for some of it, and there were certain processes that they weren't covering. So at my first visit it was like a hundred and some dollars. So the window for KDP to pay for was like 60 days or maybe 90 days. But for me, I am living form government check to government check and I don't have money to put off to the side you know. I'm looking for a part time job in the process so maybe things might change.

*Don't let them drop you off the process. At some point they might think that you are not interested.*

**I was there at the dentist and they wouldn't do it without the money, and I didn't have the money. Like right now, I don't have the money to get it done.**

**So there are other things too, you know. Like I got a criminal background.**

*So it makes it hard to get a job*

**I can't get a job, so it's crazy. What's the point of sending me through the process of jail or probation and then get out and can't do anything. You know it's how the background coming up. What's the point of serving your time and everything when you don't have the money to get the thing off your record and when you go and try to get a job, you know. What's the point of looking at my background check if you**

**are going to discriminate against me and I can't get a job..I mean....the jobs that I am looking for are cleaning and I can sweep.**

**If I could get a part time job I wouldn't have to count on someone else.**

*Will that eventually come off of your record?*

**You got to pay to get it taken off. It takes money**

*You have to pay?*

**It's call expunged.**

**Each individual thing that is on there you have to pay to get it taken off.**

*So is there a lot to get taken off?*

**Well, yeah, well it's like even if you are charged with something it's still on there.**

**Which is ridiculous. If I am innocent until proven guilty why are the charges keeping me from getting a job. I went to a cleaning service and I never shot or stabbed.**

*So, they weren't violent offenses?*

**Violent offenses don't necessary mean violent. You know like drug charges and stuff are considered violent....certain ones...so it doesn't necessarily have to be violent to be considered a violent crime.**

**It's even to the parole board and everything like that**

*Oh, I don't know anything about that.*

**Yeah, I know. Well, put it like this a felony drug charge..**

*Possession?*

**A Felony, well possession is a misdemeanor..**

**Sales and conspiracy and stuff like that are considered a violent crime.**

*Do they cost more to get expunged?*

**I am not sure. IT all costs. I don't think it is more for this kind and that kind. It's like thirty or forty dollars for each one. But I gotta do something about that, and I gotta get a job.**

*It's good to hear that you are so positive about that. You do have a lot to contribute, and you do seem like a really smart guy. We do pay for our past in one way or another.*

**It's not like I wasn't told beforehand that that was going to happen.**

*How old were you?*

**Young**

*And you think you can just get away with it.*

**Yeah, and I am having the same discussions with my daughter right now. And with my son.**

*How old are they?*

**Fourteen and Sixteen. I tell them, you know the decisions you make now they will be with you.**

*Yep, you have got some hurdles there, but I think you have got a really good attitude.*

Larry: Interview 1

*The reason I am doing this study.....Do you just have any general comment?*

**You can get started**

*When did you first consider a transplant?*

**(Pause) It's been a few years ago**

*A few years ago?*

**Yeah**

*Did somebody refer you (to the transplant program) like your doctor or someone here at dialysis?*

**Someone here at dialysis.**

*Did you have to wait long for an appointment?*

**No, not really. When I first started I had a whole lot of different things going on and, I had a lot of different health issues. And every time I got started something else would come up and I had to just start over again. Every time I would get almost done I'd have to start over again.**

*Did the staff here help you with that?*

**Yes.**

*Was there a family member or a friend that you involved in your decision.....*

**No.**

*That is something that you decided all on your own?*

**Yeah**

*So, do you remember about when you met with the transplant team?*

**I can't remember when it was now.**

*Did you have to wait a long time for an appointment?*

**Ummm, no. I didn't have to wait a long time for an appointment because when I decided it was made right away. But like I was telling you I had a lot of health issues going on and they needed to keep rescheduling and keep rescheduling.**

*Has that settled down now a little bit?*

**Yes**

*What was it like to meet with the transplant team? I mean, did you come away feeling like you got your questions answered?*

**I really didn't have any questions for them. I mean they just explained everything to me.**

*And you understood what you needed to do?*

**Um hum.**

*How did you feel you were treated at the evaluation appointment?*

**Excellent**

*What about since then. Have you needed to get back in touch with them, or had any questions?*

**No, everything is going fine. I mean everything that wasn't going fine, that was on my end, my part.**

*Do you think that the first time you tried to do it it was more than you expected-in terms of the follow up appointments?*

**No, it wasn't more than I expected it was just that I had a lot of health issues going on. I had a whole lot of appointments. It was just I had a lot of appointments all together or it was (scheduled for) so far off that I would forget about it.**

*That is a very good point about appointments far off.*

**I know a lot of times I can take an appointment, and they give me a little card, I write out an appointment slip like this (shows me 8 1/2 x 11 paper) and I take it and put it somewhere I know I'm going to have to look at it every day and I'm still going to forget about it.**

*Were there any concerns or questions that you felt that you couldn't talk about when you were there?*

**No**

*What are the next steps? Where are you in the process?*

**I am done**

*So you are done and you are on the list?*

**The only thing I have to do is the stool sample, that's it.**

*Um, some studies have shown that African Americans as compared to whites.....do you have any thoughts about that?*

**I don't know if it's true, but as far as completing the evaluation, as far as myself goes, I was getting tired of all of the appointments. I was getting tired of it and I was thinking of saying "the heck with it". I want to live a little longer, so I just stuck with it. Even though I was going through all of the health issues and I had to start all over again, I just stuck with it.**

*Uh huh, so it takes a certain amount of stick-with-it ness.*

**Uh huh. I think it's been about two times when I was almost finished with it and I had to start all over again.**

*Congratulations for finishing it!*

**Yeah, I think the hardest part for me was the stress test. For some reason they didn't want to put me on the treadmill, and they put me on the thing where they .... Inject you with medication to speed up your heart?**

**Yeah, and that is very scary.**

*Do you think you could have done the treadmill?*

**I did it. I did that last Tuesday. And I felt like I could do it because I do a lot of walking anyway. I don't walk that fast though. I was ready to quit.**

*You are probably on medicine for your blood pressure that makes it hard for your heart rate to speed up. That makes it a challenge for the stress test.*

**Plus someone was telling me that a person with cocaine, that can stop your heart rate from speeding up.**

*Do you mean like current (cocaine use) or in the past?*

**In the past. It don't matter how long ago it was.**

*Cocaine can have effects on the heart like that.*

*So they had given you the stuff to make your heart race?*

**I had to do that twice. And then the second time I thought everything was alright. I thought I was finished with it, and they called Dorene and told her that I had to go**



through that again. But I had already told her I'm not going to do that fast heartbeat thing again.

*So that is why you did the treadmill test?*

Um hum. If they had told me you are not going to get a transplant then I just wouldn't have been on the list. It is very scary. There is a chance you can have a heart attack. To me it's no comfort-you have got a doctor standing here and a nurse standing here-that is not a comfort to me because once your heart stops there is no guarantee that it is going to start back up.

*Yeah.*

As far as that heart-stopping stuff I have experienced that before...IN the hospital. *You did?*

Um hum.

*Your heart stopped? Or you had a heart attack?*

Well, I came in for something...I was still using then but that's not what I came in for....and they ask me "do I think I overmedicated myself"? And I really couldn't answer. So what they did, without my consent, they gave me some stuff that made me go into withdrawal. And when they did that I had a seizure. Then my heart stopped.

*Do you remember that happening?*

I don't remember it happening, but when I finally regained consciousness I had a gash in my tongue (I bit my tongue)

*So is that when you stopped using anything(drugs)?*

No, I wasn't ready to stop. It got to the point though, when every two weeks I got admitted to the hospital.

And um, they had a program over at Baltimore City Hospital called "First Step". And about the last three times I was admitted to the hospital maybe three times within a two month span. And each time I went in they had a representative come and talk to me about their drug treatment program. And this time the guy comes in and started talking to me and I was laying there thinking "I'll be glad when this guy leaves"...so then they would tell me "you don't have to tell me now, I'll come back later on". Then usually when they do that you're getting ready to get discharged. The first time I couldn't wait to get out of there. So even though I hadn't used in a couple of weeks I had it in my mind that I ain't going to use no more. But it's different when you leave that hospital because you are going back into that same environment. And two weeks later I wound up right back in there and they had another person come talk to me. I said "I'll let you know". And the last time I went in there all that stuff (the seizure story above) happened, and they guy came and talked to me and the way he talked to me wasn't like he was trying to convince me. He was like "look man, you're killing yourself.....we've got an excellent program here I think you could fit into it. You look like you're tired man." He said "I'll tell you what I'm going to do, don't say nothing just listen to me. I'll tell you what I'm

going to do. I've got a couple more stops to make and I'll stop back to ask you what you're going to do."

*So he ...*

He knew I was already thinking about it. And then as soon as he left they came and said "Mr. Knight, you're being discharged." I didn't know they were going to let me out of there anyway and when they came and told me I was like...Aw man...I'm going to go right back out there and do the same thing. I'm looking out the window..that was before they started doing all those buildings out back there. That neighborhood was drug infested, and in order for me to get home I had to go right through it and I knew what I was going to do. I was just standing there and looking out that window and I said to myself "I don't want to go back out there because I know what's going to happen and I may not be so lucky this time."

So, when they told me I was going to be discharged, they told me I was going to be discharged today, he said "no set time, just take your time and let us know when you are ready to leave". I took my time fiddle faddling around and about three hours later I had put my shirt on, and my sox on but three hours later I still hadn't put my pants on. I was trying to prolong it hoping that the guy would come back.

*Did he come back?*

So I finally got dressed, grabbed my little belongings and I'm ready to go. As soon as I got to the door there was a "knock knock". He said "you leaving?" I said "yeah", he said "where you going?" I said "wherever you're going to take me at". "Wherever you're going that's where I'm going". He shook my hand and said "follow me." And ever since then.....

*So, are you still in touch with him?*

Um hum. Good friends.

*I bet you are.*

I see him at meetings and stuff like that.

*I often wonder about how people get to the point that they can leave that behind.*

It's not easy.

*I'm sure it's not. I think it's different for everyone.*

It takes a lot of hard work. You can't just say "I'm clean" you know?

What it is it takes something like that to make it sink in "I'm killing myself". A lot of times you say "I'm not hurting nobody but me", but that's not true..you're hurting everybody around you.

*Do you work with that group now?*

No, but after I left First Step, see it's a two-stage program. After you leave first step they have another program called Nine Eleven...right a couple of blocks down Broadway. It's intense inpatient and outpatient treatment. When I went in...

*Is First Step inpatient?*

It's inpatient-intense inpatient. First Step, when you agree to be in the program you go from your room- to them and when I first went they had like one big room and you are in that room all day from seven o'clock in the morning to seven o'clock in the evening. When you leave at seven o'clock in the evening they escort you out to the door and you've got a van sitting out there waiting for you. You get on that van

and the van takes you to a recovery house. You get to a recovery house, you get out the van and go straight in the house.

*Where do you eat?*

At First Step they feed you three meals; breakfast, lunch, and dinner. They give you a menu just like patients. You can order as much as you want. That part of the program is like maybe eight weeks. Then you go to Nine Eleven and that can be anywhere from six months to a year. And I'm still involved with that program now.

*The Nine Eleven program?*

Yeah. It's a lot better than a lot of these other programs where you just go there, get medicated, and leave.

*I had often wondered about that and had not really looked at the success rates.*

The success rate is not very high because you don't have no structure. Nobody looking over your shoulder.

*Are you allowed to see your family during that time?*

**When?**

*While you are at the First Step?*

Yeah, they can come in and visit you. But if they bring you...anything they bring you they going to go through it even before it touch your hands. Like if they bring you clothes.....they search everything.

*They probably have to.*

Um hum. Yeah because you've got some people in that program not because they wanted to stop using but because they wanted to be inside and not out in the street in the wintertime. And as soon as the weather would break, they're gone. They had this program on called "Turning Point", and it's run by a preacher and he did good work for the community period, but they call that program a "Gas and Go". What that means is that you just go there and you get your medication and you're gone.

*Not a whole comprehensive program.*

And you might talk to a counselor maybe once a month. But this program is like \$265.00 a month or \$10.00 a day and most, I'm not going to say a majority but most of the people in the program are members of the church too. So you can say it's like a.....

**I'm not involved in his program but I attend his church.**

*So, the Nine Eleven program.....are you still involved with that and do they have things further out for people who want to maintain their connection?*

I mean even if you get through with the program you become an alumni and you can go back any time you want to. You can go back and share messages of hope with them and with newcomers and stuff like that and volunteer your services.

*That has to be a lot harder than getting through a transplant evaluation.*

**It is.**

*So you knew you had the fortitude to get through that.*

Well, I've always been a person who when I start something I like to complete it. I don't do it half way or start it and then quit. I used to work for this Jamaican guy when I was working under the table. He owned a garage-an auto mechanic shop. And the first time he asked me to do something for him, he was hanging at a bar

down the street and he said "do you know how to do breaks?" I said "yeah". He said "do you think you can put breaks on the front of that car?" I said "sure". He said "you go ahead and put those breaks on and I'll pay you". And I just looked at him and he said "what's wrong?" I said "Man, I don't know you". I went on and did the break job and by the time he went across the street I had the car jacked up. Before he finished his drink I had it finished.

*Are you still working?*

No, sometimes, sometimes. I did that for, I started it before I found out my kidneys was messed up. Then when I found out my kidneys was messed up I started working for him. And I worked for him for I think about maybe like almost as long as I have been on dialysis. I just stopped working with him about three years ago. The last time I was admitted to the hospital for something. I was on the third shift then, and he'd pick me up and bring me to work until 1:00. And where the shop was at I could just jump on the subway and I was here in about four or five minutes. They used to hate it when I'd come from the garage. When I was here, you could tell I was here when I left. I'd be all greasy and stuff. You could tell everywhere I'd walked because I didn't change my shoes.

*Well, is there anything I didn't ask you about transplant that ..... When I come back*

Larry: Interview 2

Initially talking about the previous snow storms (2010) and how he and his neighbors got together to shovel the snow-what a great story teller he is!

**I don't think I'm going to be doing it (shoveling snow) this year, because last year I felt a twinge in my chest. That was my cue to quit.**

Another story about a winter ice storm he went through when he was in the service (Army) in Virginia.

**Ok now, so let's get started.**

*The last time we met we talked about.....are there things that you need to do in terms of the evaluation, that you found difficult to accomplish?*

**No. I had so many appointments, like one after another, but it was no problem as far as setting up the appointments.**

*And what about coordinating your appointments with dialysis?*

**That was no problem because the appointment was always on my off days.**

*Tell me about the kind of help you got here at dialysis regarding your appointments.*

**Lisa made sure, she kept reminding me every time I came here. She knew I had a habit of forgetting appointments. She would remind me and then I'd still forget.**

*She has been able to be very successful in getting her patients scheduled and reminding them about their appointments. That is a help on the transplant side too, because we can easily make contact with her and we want you to get through your evaluation too. There are so many things that can come up along the way.*

**It's just like now, everything's done. I just did a what do you call the roto-rooter, uh..**

*The colonoscopy?*

**Yeah, I did the colonoscopy about three years ago and she said I've got to do it again because there was blood in the stool samples. And I told her, every time I get almost done, something's going to come up.**

*Is she going to have you repeat the stool tests or do you have to go back to the gastroenterologist?*

**I have to go back. She hasn't set the appointment yet. Some of them don't like to see me because I have that factor 9 deficiency. She was trying to see if she could get me right through without having to go through that (hematologist first).**

*They don't want to put you at any risk.*

*Have you had any thoughts about why African Americans may be referred less often than whites for kidney transplant?*

**I didn't even know that.**

*Do you have any thoughts about that?*

**Not really.**

*The last time we met we talked about whether or not a family member or friend.....to pursue a transplant and I think you said there wasn't somebody.*

**No, that's my decision.**

*Is there anybody pushing you to get done or anybody at home that is a real advocate for you?*

**Well my family, they're behind me, you know.**

*Is there anybody else in your family with kidney failure?*

**No, just me.**

*Anybody with high blood pressure in your family?*

**Have an aunt. I think that's what caused her death-kidney failure. She was almost 90 years old though when she died.**

*So, you don't feel like there is anybody in your family that's particularly pushing for you to get a transplant.*

**Uh uh.**

*So what thoughts or concerns might you have about when you get the kidney? Thoughts like getting through the surgery or after the surgery-what you care will be like?*

**I have no problem with getting a kidney or those regimens I have to be on.**

*Do you mean the medicine regimen?*

**Yeah, but what really concerns me but not a whole lot, is I hope it don't fail.**

*Have you known anyone here (at dialysis) who has gotten a transplant?*

**There's been a few here.**

*Did anyone's fail?*

**Well there's two people and they are doing real good. Matter of fact we had one guy here who works over at Hopkins and there was another employee there who gave him a kidney.**

**We had one lady here, she got a transplant and she just died. That kind of scares you.**

*I bet that does scare you.*

**Makes you want to take a pause, you know. I hope that doesn't happen to me.**

*That is why all of the testing ahead of time is important.*

*What about the medicine regimen afterwards?*

**What about it?**

**I'm used to taking pills, so that shouldn't be a problem.**

*Do you think it will be an adjustment not to come to dialysis?*

**I know there's probably going to be days when I forget and I'm sitting right out there and people's going to think I am crazy.**

*Well, people will appreciate a visit.*

**I don't think I could stay away anyway. It's like a little family here.**

**I've been here a lot longer than some people that's working here.**

*Maybe you could be a transplant ambassador, or help Dorene keep people updated on their transplant testing. That wouldn't be a bad job.*

**It sure wouldn't. Maybe I could do something like that.**

*Do you think you will go back to work?*

**Probably so. Really, I was working almost the whole time I was on dialysis.**

*You told me about the mechanic work you did. Is that something that you feel like you still have the interest and the energy to do?*

**Um hum. The only thing about that is you get tired of the grease and the grime all the time.**

**You see, I don't want to get back in the heavy stuff like pulling transmissions. I would want to do break jobs, simple stuff. If I have to I'll do it.**

*What are your thoughts about the kidney donor?*

**I guess either way it's going to do what it's going to do anyways.**

*Do you think.....fair to African Americans and whites (fair distribution of organs)?*

**...pause for a while....I really can't say. You know I never read up on it so I can't really comment on that.**

*Do you have any religious or faith based beliefs that are in conflict.....?*

**No**

*Do you think that getting a transplant is in any way an experiment.....*

**No.**

*Is there anything about your beliefs .....*

**Not really.**

Beckett: Interview 1

*My intro....what do you think?*

**I think that a lot of patients the main thing is education because the knowledge of what you got to go through, because a lot of people, they are scared, you know a lot of black people you know, they don't want to go to the hospital. Period. And then when you are talking about operations, they definitely don't like that, and when I talk to them, somebody has talked to them and gave them information that scares them and the information might be wrong. A lot of it is wrong. I think that's one of the main problems, and I try to tell new patients when they come in here; 'you've got a few things that's most important, first think is you what to get that catheter**

out of your chest. I said, that's real important. The second thing is to listen and pay attention. Everything somebody says. Even if it seems like it don't concern you. Like, I have a lot of people talk to me about diabetes, and even though I don't have diabetes, I still try to learn about it. And a lot of people don't. They don't want to listen because they think it don't concern them.

I have been on dialysis, my first time, it's been thirteen years..... After they started it (the kidney) back up it ran for four years (*I believe he meant weeks*)

.....I think that did help me because when they did shut back down I had already had been dialyzed before and I knew what to expect. And my kidneys was only down for like thirty, maybe forty days before they started back up, so I had the experience. I think a lot of people just got...well, you fear what you don't know. The more you can learn about your sickness, the less fear you are going to have.

And another thing I tell Doreen (the NP), You know I always joke about it. I say they need a head doctor on all the time. You can come in here laughing and happy and feeling good and by the time you get off you're feeling bad, and that can make your whole demeanor change. Then some people, it's hard to talk to people about it because when you go home and you are around your family and you try to talk about what is going on in here, and they don't know nothing about it,

*Do they have opportunities for families to come in and see what it is like in dialysis?*

Um, I think years ago they did. I joke with the techs when they start. I say 'y'all should have to sit in this chair for four hours. That should be the first training you got. A lot of them say "why do you want to go to sleep?" And I say that's why you need to experience sitting in this chair for four and half hours.

*You were starting to tell me about when you go home and talk to your family...you want talk about it but they don't understand...*

They don't understand what you going through. It's really like, you're talking and they don't understand and they can't get through the conversation with you. But, um.

*You've been on dialysis a long time.*

Well, thirteen years.

*How old are you?*

Forty five. And, but I was worked up the first time at County General Hospital (for transplant)

*That was my first question-when did you first consider a transplant- so you are following right along here... so did you say four years ago?*

No, it was longer than that. I was worked up at University about eight or nine years ago,

*So, shortly after you were on dialysis..*

Right, and I stayed down there and I never got called for a transplant. So they said I need to lose weight. And they never called me. They said I was activated and I was accumulating time, but they had a stipulation saying I had to lose weight.

Because when my kidneys got started back the first time, the thing that started them was I had to take a hundred milligrams of prednisone every day for a whole year. And then, from my 100 mg after being on it for a year, they had to start weighing

me down. And it took almost a year for them to weigh me down. I got moon faced, and I gained all this weight. But since I've gotten off the prednisone I have lost about a hundred ten pounds. They wanted me to lose a hundred twenty pounds. Now when I got to Dr. Stewart, he wanted to know why I wasn't worked up over here (at Baltimore City), so I got worked up over here and I talked to a surgeon and the surgeon said I see no reason why, you know, this was maybe like two years ago when I first got worked up, he said I feel comfortable doing a transplant on you. So he went over everything with me and he said "ok we're going to get you worked up". So they got me worked up. They got a list, I guess from the kidney foundation of what your weigh and your height should be and I was about eight pounds over. Well I got down to two pounds over that and they called me up and they told me that they activated me, and now you can get a transplant. But somebody had made a mistake, and they said that they sent me a letter saying I could get a transplant at any moment and that they got my transferred stuff from County General, and then about a month later, I got another letter saying that because of the two pounds, they got to take me off of being active. I and I was like "Whoa! Because of two pounds you going to take me off the list when the surgeon he said, um he said everything looked good."

*Do you remember who the surgeon was? I bet I know what could have happened.*

*No, he said everything looked good and he felt comfortable doing the surgery.*

*Every transplant center's surgeons set the expectation for the patient's weight. They are the ones who do the surgery, and they know what is the safest for you.*

*That's what I thought. As a matter of fact he got upset because he called Dr. Stewart and asked Dr. Stewart why he had not had this patient worked up before. He said he gave him an earful because he thought he had not sent me to transplant. He explained that he was new as my doctor.*

*There are not many surgeons who would give Dr. Stewart an earful- I don't know who that was!*

*Repeats the story.*

*And to get the letter a month later saying that I couldn't be on the list because of two pounds....*

*How did you feel?*

*I was like, "I'm not going to worry about it anymore. I'm not going to get my hopes up for it. IF I get it I get it."*

*So, where are things now?*

*Well...*

*Did you transfer your wait time from the County General to the Baltimore City list?*

*They said at first County General told me that they would do that. And um, for some reason they called me back and they wanted me to stay with County General. And they told me that they thought they could, but they couldn't transfer my time. Then um, the coordinator... I had already told the coordinator I had over here, about the time and the paperwork that the old coordinator at County General had, and I think that they did transfer the time. Um, but, yeah they told me "why do you want to change to Baltimore City?". I told them I dialyze over here and my doctor*



is over here. Then they said that they couldn't transfer my time. I told them that the coordinator told me I could and that I had almost five years' worth of time in. And she said that it was a mistake and we can't do it. But I think they was just trying to keep me from leaving.

*You should pursue that to make sure about the time. If you transferred five years of wait time and you are within the weight range you should be getting offers soon.*

**I think they did transfer the time. I think that was kind of a scare tactic from somebody to keep me.**

*So when you came here (Baltimore City) you had already been evaluated somewhere else.*

**Right.**

*So, did you initiate your own evaluation at County General?*

**Yeah.**

**At the time, when I first came here, they were doing so many transplant s at County General, that in my mind I went there because I thought I would get a transplant right away. But that was a mistake, so I came back here.**

*Was there a family member or a friend who helped you with the decision (to get a transplant evaluation) early on?*

**No, basically. Well, I don't have no brothers or sisters. My mother is elderly. AT the time my kidneys shut down, she was working over at Baltimore City Hospital. She worked at Baltimore City for 48-50 years.**

*She did? Oh my goodness!*

**My stepfather worked there for about 28-30 years. When my kidneys first shut down I believe she was still working there. And I ain't got no brothers and sisters. So when I was going to the little seminars and things like that, I think they was working and a lot of times I just didn't want to bother them and have them take time off work. I just went to it on my own. And not only that, when I first think when I first started out I didn't mind going on my own because I could focus more on what was going on and being said because I was more interested in just learning and get as much knowledge as I could. But like I said I think they should have programs for the family. I think I have heard about a few programs where they say to bring family members. But it didn't seem like it was something where they was trying to give you the knowledge from the beginning. You need the knowledge from the beginning-like what caused my kidney failure in the first place. When I went to my parents to try to explain it I started with what caused my kidneys to fail. *Are your parents both still living?***

**No, my father passed away. Last, matter of fact the eighth of last January....it will be a year tomorrow. He had cancer. But uh...**

*So, do you live with your mom? (he nodded) How is she doing? Do you need to help her out quite a bit or is she able to help you?*

**Well, we help each other. Um, I try to keep her, like I said it's hard to get the older people to go to the hospital. She had a cough and said it's nothing wrong just my sinus draining. It took me about a month to get her to go to the hospital. She went and found out she had a lung infection. She got an antibiotic. She don't like taking**

**pills. So I said, see, if you'd have went when I told your four weeks ago you might have been able to avoid taking as much medicine. It's just they scared of hospitals. And she worked in a hospital for a long time. What department did she work in?**

**Purchasing**

*When you went for your evaluation did you feel that there were things that you couldn't talk about with them?*

**No.**

*How do you feel like you were treated?*

**I felt like when I was evaluated I was treated good...by the surgeon he gave me good information and he assured me that my surgery wouldn't be no more difficult than any others. He explained all that to me. But what I couldn't get over and what I still can't get over...because when they called and told me about taking me off the activation list because of the two pounds, the first thing that came to my mind was to ask them this question. I said 'so you're telling me if I was sick to the point of dying and a transplant would have saved me and I was not activated because of that two pounds you all would not have given me that kidney' and she said well, if you don't meet the criteria, no we wouldn't. I kind of feel like when I make a mistake dealing with my sickness I pay. Whether it's I've missed time I'm going to pay because I don't want to go in the hospital, or I'm going to wind up unable to breathe because I didn't do my treatment. So at the same time when you all make a mistake and it's a mistake that the surgeon said, hey that two pounds is not going to put him in no jeopardy....**

*I'm wondering if it's a different surgeon now. I know there was a change a couple of years ago.*

**That was one thing I was told too.**

*The surgeon who is going to do the operation on you is the one who is going to call the shots because he is the one with the knife. There is a new guy who came about two years ago.*

**And I was told that it might be a different surgeon. One surgeon felt one way and this other surgeon felt another way. It's just two pounds.**

*Can you manage to lose it?*

**Well, since that I done gained about five pounds, but now I'm about seven pounds up.**

*I think we all gained about five pounds over Christmas.*

**That's what I was going to say, and that's because of the time of year that it was. If it was the summer and it was warmer...**

*You should have quite a bit of time now. You know you continue to accumulate time when you are inactive.*

**Right.**

*So as soon as the weight comes off, you have so much wait-time, you should be able to get a kidney pretty quickly.*

**Right. That is my main thing that I have to work on...getting the weight off. I cut back on my food, but because of dialysis it drains me and makes me feel week so much. I come to dialysis Monday and get my treatment, I go home I'm in my**

bedroom, I look at my TV, until it's time to leave out and go to dialysis Wednesday. That's how weak I be, that's how tired I be. And on top of that you know men having the egos that we have, I say I'm not depressed. I say it to my mother and to Lisa, but inside I really know that I may be. Plus over the holidays, after that happened I got depressed to the point I say I'm not going to let them build my hopes up. I am not going to get my family's hopes up and then have to tell them they took me off the list because of whatever it may be. Because then I feel like you was activated and you did what you have to do and because of something of what happened I failed and I messed it up. It's a lot of things.

*If that is your goal, you will get there.*

When I was last, right after they sent me the letter I started losing weight. Now I'm going up for two or three months. Then the holidays came. I automatically know in December I am not doing as much and I am in the house and eating. So, I said after New Year's I'll deal with getting this weight off. I got me an exercise bike. And I got me some weights.

*Some free weights?*

Yeah, some free weights, but that was a problem because I wasn't thinking at the time and I got too much weights (for the arm with the dialysis fistula), so I got three pound weights that are safe for my arm.

I have a stent in my neck that has about 100% stenosis in it. I have had this fistula for about five years. Since they placed this stent in my subclavian it has gotten worse. The collateral rays that grow around it keeps the fistula working and I'm still getting dialyzed, but they say that if it gets clotted off they are not going to fix it. Basically they will need to give me a new one. So I am trying to take care of it. The stent has folded in half and it's calcified and they can't get the balloon through it.

*Gosh, it would be nice if you got your kidney before you needed another fistula.*

Yeah.

*Do you ever write stuff down that you eat to see what you are eating?*

The dietician told me about the week before Christmas to write down everything you eat, and I didn't really start that. I told her Christmas is four days away, let's start it after New Years'.

*You could start next week.*

Yeah, I'll start on Monday. I'm going to start exercising again around Monday.

*You'll begin to feel better.*

I feel so weak from the time that I leave here until I get ready to come back in here. The family, they call me up about cook outs and parties and I never want to go. Lisa said "maybe you depressed" and like I said, "I know I'm not depressed". They sent me to see a psychiatrist because they said I was having anxiety attacks. I was taking a blood thinner because I had a blood clot in my legs that nearly killed me. After I survived that, they put me on blood thinner. And the whole time I was on a blood thinner they thought I was going to the emergency room so much, but I was going because the hematologist told me to go to the emergency room if this happened and that happened and that was why I was going to the emergency room. And they started saying I was having anxiety attacks. I said no, I was following

orders. When I got there my INR was too low and not therapeutic, and they thought I was just having anxiety.

*So is that still going on?*

No, because Dr. Stewart took me off of the blood thinner. He said that he didn't think it was necessary. He took me off the blood thinner about three months ago and I haven't been in the emergency room but once in three months and then I had an infection. I was going every week two or three times, and I was having chest pain. I'm not saying I don't have anxiety attacks. I do have anxiety attacks but it's when I'm on the machine. I start sweating. I can take one pill and it will go away. I talked with Lisa the other day about needing some energy.

I think the only thing I can do is to do it in baby steps.

*That's right, and you need to feel like you are making progress.*

When I lost all that weight. I realize that we use food like a baby uses a pacifier. I found myself using food. I look at a football game and I've got to have a sandwich. That's the 1:00 game. Then there comes the 4:00 game, I gotta get a snack. I caught myself one day watching the game and I was eating a sandwich and I thought, I'm not even hungry. I'm running downstairs and I'm really tired, and I'm huffing and puffing and coming back upstairs with this sandwich, and I realized I'm not even hungry, so I said I'll eat when I get hungry. Over a period of time I found that I would just eat twice a day. Most dieticians would say that's no good- you should eat four small meals. But I try to explain I just eat when I get hungry, and when I do eat it's not a big deal. Because I'm not active my body doesn't require as much food. With my two meals my weight came off. I think I am going to start back on that.

My other big problem is cigarettes. When my mother found out she had that lung infection a month ago she stopped smoking. I'm down to 3 or 4 a day now. I want to stop all the way. I try to keep track of when I smoke. When I get up in the morning and I'm by myself, and when I get home from dialysis and I'm by myself, and that's when I smoke. If I'm out and around people I don't.

*That sounds like you are doing a good job. I am a strong believer in writing it down so you can see your progress.*

*Some studies have shown that African Americans.....*

I think that's true, um the reason why African Americans have more kidney failure is because of circumstances....not taking care of high blood pressure, and not taking care of diabetes that leads to the kidney failure. But uh, that's the main reason why they have more. And as far as them not finishing the evaluation, I think like I said education. I think they need more education. I think they need to know what they got to go through, why they need to go through it, and um, and letting them know hey, this is what everybody got to go through. They not checking your lungs just because they want to check your lungs. A lot of people don't realize that.

*Do you think that is African Americans or do you think it's people in general?*

Well, what I learned is that African Americans and other people like in Mexico and all those little countries, is that they uh they just scared of going to hospital. And like I said when you are already scared of going to the hospital and the last thing

you need is incorrect information from somebody who my cousin was on dialysis and this is what happened, etc. Everybody's situation is different.

When you give somebody information it can't be somebody else's experience but it may not be specific to that other person. It's easy to scare people with that kind of information. And another thing, uh, about African Americans and other people of dark complexion they don't have or they don't believe they have access to the medical that they need. That goes back again to education. They don't check into it. They don't have computers and they don't know how to get on the internet to check into it. So that has a lot to do with it.

*Most people don't know what their kidneys do, and don't have appreciation for them.*

It's sad to say but a 16 year old boy got shot the other day, nine times, he died. In my community young, strong young males and females is dying at an alarming rate. But because their parents and their loved ones don't have the information they don't want to donate their organs. That's a lot of organs that could be used. But because of some religion, even though the religion doesn't do that they say it's because of their religion that they don't want to donate. All you got to do, when you go get a license is to sign up to be an organ donor.

*I think that is getting better though. Over the past five years or so they have worked very hard in the minority communities around understanding and focused understanding.*

I have told my little cousins when they get their licenses. I ask them to look at their license to see if the heart is on there. I don't know what that is because I know I'm not going to need organs when I'm gone.

*I think it just takes a long time to change some of those beliefs. Next time I am going to ask you more questions about those things.*

*Is there anything else that I didn't ask you that you would like to talk about.*

One thing that I think is that we as patients should have some kind of meeting of the minds of patients every or every other month with someone there who can help put things into effect. That we don't have. I would like to suggest that to Dr.(medical director). I think you need that a lot. I know that not all the patients on this shift will show up, but it could just be about little things. When you have been doing dialysis as long as I have you see so much happen. I've seen a lot of mistakes happen. These techs and nurses work 14 or 15 hour days. When the third shift gets here they've been working 10-11 hours already. You are going to have mistakes but you have to try to keep mistakes to a minimum.

*That's a good suggestions.*

There should be a meeting where patients and staff can sit down together in a meeting.

*You have some great ideas. I look forward to coming back and talking with you in about 3-4 weeks.*

Beckett: Interview 2

*Well, the last time.....have you had any additional experiences with your transplant evaluation since we met?*

No. Well, I did all of my tests, and um, when I told you at first when I did my test and talked to the surgeon he said "I feel comfortable doing the surgery on you".....since then I've gained another twelve pounds. Now I'm trying to get off fourteen pounds. And until (since) last week I've been exercising. I told Dr. Stewart I've been exercising for the last week.

*You told me the last time you had gotten an exercise bike and you needed to get someone to help you bring it upstairs and put it together.*

I got it. On dialysis days I ride the bike. I ride it a little bit in the morning and a little bit after (dialysis). And then on non-dialysis days I've got the three pound weights. I've been working with the weights. I don't want to mess with the weights on dialysis days because my arm might be bleeding.

*I'm really glad you started that. Good for you!*

Yeah, but after my fourth or fifth day I was hurting so bad, my legs and my chest. I could barely get up out of my bed. I bought me a tube of, like icy hot in a tube of deoderant where you rub it on. I got that and some Advil. I like the icy hot better than the Advil.

*So what are you doing with writing down and keeping track of what you eat? Did you start that yet?*

*Tomorrow is February first- a good day to start.*

But it's kind of hard because for one thing since I seen you, I'm only eating one meal actual meal a day. I'll eat my meal around this time of day, maybe three or four o'clock. And then if I get hungry at night I'll have Jello, applesauce, or Honey Nut Cheerios. I am going back to that. Because when I did that the first time I lost something like a hundred pounds.

*Have you lost any weight?*

No, I havn't. I haven't really been watching that yet. Like I said this is only my fifth day, so I will start weighing myself.

*Snacking can put on a lot of calories. That is why writing it down can be very helpful. I just don't want them to take you off.*

Take me off? The waiting list? The way they explained it to me was that I was still accumulating time. They shouldn't be able take me off. Once I reach the goals that the kidney people have, I can be active and be able to get a kidney.

*I hope you can do it. The exercise can help you a lot.*

But I was telling the guy the other day, I kinda had thought about it and it seemed like I actually, when I got sick I gave (up) a lot of my life. And I said I gotta get my life back..like I told the doctor I want my life back. Because when you go on dialysis don't mean like me and everybody in my family says Mac, won't you come out, and when they have a cookout they ask me why don't you come out you always making excuses. That's what I mean when I be saying I not only lost my kidneys but I lost my life.

You don't feel like, you know you just so weak. That's why I started exercising because I need to start feeling like socializing more. But, I leave here, I go home and I go to bed.

A lot of people say that they think I'm depressed but I'm not depressed. I'm just physically weak. They can't understand it because they (are) used to seeing me (as a) football player and in school playing basketball, and every time there is a cookout or a function or a wedding I'm there....No it's like every time I ain't there some people might say I'm depressed or mad at somebody. They don't understand I'm just tired. Until you walk in my shoes don't try to tell me. Until you have been on this machine and you can feel the ramifications of being on it, how weak you feel, you get sick. As soon as you get better from that something else comes up. And so, they just don't understand that. And I understand why they don't understand that because they never went through it. I don't get upset with them or nothing.

*But you are doing the right thing starting to work on the exercise.*

At night I sleep on CPAP but I also have oxygen on. Since I've been working out I always got to use the CPAP but I went to sleep a couple of nights without the oxygen. The first time I fell asleep without the oxygen and the CPAP. That was a mistake to do that. But I noticed I didn't keep waking up every hour. And when I did wake up I noticed my heart wasn't racing. So it made me think..maybe I can cut back on the oxygen since I've been exercising, and keep the CPAP on. So I haven't been using the oxygen as much.

*Tell me how you are doing with giving up the cigarettes.*

Allright, that I got a little better. I've been chewing chewing gum some days. And um, I had got myself where I was taking four or five cigarettes a day and make them last the whole day. But on the average I might smoke seven or eight cigarettes a day, but I said I'm going to start weaning myself off. As you exercise you don't have the craving as much.

And um, on my off days I haven't been going out of the house but I sealed the windows with the plastic, and another day I got up and I had to hook up some new phones. And today I went and bought some stuff to seal the doors so tomorrow I'll have that project. A few little projects around the house to keep myself moving. Like I said I'm taking my life back. There is no reason just because you are on dialysis, that you have to confine yourself like that.

So that is where I am at right now. And I had asked Lisa about this Dictaphone (digital tape recorder I am using), where you get them because I want to start writing my book. She told me to go to a place where you buy office supplies. Where did you get yours?

*I got mine at Best Buy.*

Do they take tapes or is it just a recorder?

*It is a digital recorder. IT doesn't take tapes. You can actually stick it into your USB port and save it.*

*So you are writing a book?*

Yeah, I'm writing a book, um I've been telling Lisa that I'm writing this book. I've been writing this book for years. And she always says "when are you going to write the book?" And I said I'm working on what I'm going to name the book.

*What is the book about?*

I want it to be about, in my head and it's two or three years in my head back and

forth about that. It's kind of, I want to kind of write a book to introduce new people to dialysis through my situation and my experiences, and let them know that because you are on dialysis. In order to write about it you have to live it. I can't be setting in the room 24 hours a day and telling somebody in the book that you can't have a life on dialysis, you know. But um.

*That is quite a goal, good for you!*

Yeah, I'm going to do that. See, that was what I was thinking. I will dictate the book and get the tapes and get everything how I want it and then I'll have to get the money to get it transcribed into book form. Just my experiences-things that I have learned that a doctor can't tell you or a nurse can't tell you, um a technician can't tell you. There's a lot of things you learn from dialysis just from being on it, and it might just fit you- because it's not because it happened to me it will happen to you. I don't want to write that kind of a book, I just want to tell them hey-this could happen to you but it won't necessarily happen this way. This is about my experience.

When I got sick I had just finished home improvement school and I got accepted into a four year program-an apprenticeship. And then two years into that my kidneys shut down. At that time when I was going into all that I didn't know anything where I thought I'd be at this point in my life. It's not a big drawn out story because a lot of people won't want to read all of that.

I want to go back to school again and I want to go into the medical field. (finish story about his being offered a job as a tech).....I worked at Baltimore City Hospital for six years. I worked driving a truck, and I worked in salvage, and I worked in receiving and distribution. My father was the manager of the receiving and distribution department. My mother worked in purchasing for 48 years-she was a supervisor. My step-father came twenty years out of the military and went straight to Hopkins as a manager and stayed twenty-seven years. So he brought me in with him in receiving. From there I chose to get with the truck driving. I want to get into the Medical field. After I got sick I wasn't able to do anything. Now it's time to get back to the Medical field. Something, I just got to think about that.

They got a job here that I think is perfect for me, um and the nurse Scott tried to get it for me before Mike and Danny was here. And the other guy had already promised it to somebody. They got a job purchasing supplies for the unit three days a week, and they don't want to give many hours. So I told them, look three days a week and no more than four to six hours a day I can guarantee you that your techs in the middle of the shift is not going to have to get up and go get this and go get that. I never had approached Mike about it and I heard that one of the techs had got the job, so she got the job.

*You've got lots of motivation!*

I'm going to wait and talk to Mike about the job. In here, doing this kind of work you've got to have dedication. Another thing I can offer is the knowledge that I have and the sympathy because I know what they going through as a patient and I think I can contribute a lot.



*Let me ask you some of my questions now.*

*The last time we met we talked about a family member or friend.....*

**My mother and my stepfather. My stepfather the first thing he said, you know was can I get checked because I'll give you a kidney. He didn't know because he was 78 at the time and he was sick and I said I appreciate it but you like drunk alcohol all your life and smoked cigarettes all your life...and he insisted. I want to be checked. I said dad, it's for nothing. The kidney foundation will pay for him to get checked, but another thing that I see is a lot of money gets wasted on things because people don't want to look at the true reality of their situation. And I think a lot of people don't want to be the ones to say we not going to pay for you to get these things done because we know your situation. You can't. Nobody want to be the one telling nobody things like that. Sometimes you have to because that money that is going to be used to get somebody evaluated is money that could be used for somebody else.**

*I know what you mean and I agree with you.*

**But um, disability is for us to survive from month to month. A lot of people waste..I see a lot of waste of uh, I see a lot of abuse. I want to sit down and talk to Mike about my ideas. The last time the job opened up I was in the hospital.**

*Do you have any concerns about the care you would need at the time of transplant and afterwards?*

**Yeah, and that's why I noticed a lot of people have disability and Medicare. And I tell them if they plan on getting on the list you have to have a kidney foundation card.**

*You mean KDP?*

**Yeah, KDP. Cause certain medications it's going to help a lot. These medications you can't take them just when you can afford to buy it. That kidney that you got in you could be with someone else if you're not going to do what you need to do to get that kidney functioning.**

*Do you feel ready to do that? To take care of it?*

**Um, I think I would. Matter of fact I know I would because I see people coming in here being on dialysis for ten months and they get a kidney. People on dialysis for a year and a half and they get a kidney. Well in a year and a half you are just starting to experience some of the things I been talking about that a doctor can't tell you about. You just starting to experience some of those things and you might get a kidney before you get to that point.**

*Do you have concerns though about yourself? About during the transplant or afterward? Or about not coming to dialysis anymore and the change that would make in your life?*

**Well, when they ask me "when you get a kidney what is the first thing that you want to do?" and I tell everybody I say that the first thing I want to do is something so simple. I want to stand up over the toilet and urinate and hear that urine hit the water. I haven't heard that in years. That's one of the first things I want to do. There's quite a few things I want to do when I get a transplant. I would come back and visit this unit, but I would never come into this part of the unit. If I have a kidney functioning and I have no medical reason to be here, I never want to come**

back here to see somebody on the machine. I'll come and visit in the waiting room and in the parking lot.

*And why is that?*

Because I think because just because I know what they going through and what they dealing with when they hooked up and I wouldn't want to see nobody hooked up to it, unless there is a medical reason for me to come back here.

*What are your thoughts about the kidney donor?*

Well, like I told you last time People when they get their driver's license they should automatically be a donor. I am dependant on getting an organ from somebody. It would be foolish for me as badly as I want to get a kidney from somebody whether it's a live person or a dead person, to receive an organ from somebody and not be willing to give an organ. If I was to do something like that I would have bad luck. I've been an organ donor since the first time I renewed my license after I got sick. But before that I was just like everybody else. I never thought about it. Back then they didn't bring it to our attention like they do now, but now there's no excuse. When I die, I'm deceased, there's nothing of my organs that its critical that I be buried with I don't think. So hey, if somebody can use them, I feel like that's a part of me that's living on.

*Do you think that the way organs are distributed.....fair equally to AA as whites?*

Um I don't think, I'm going to be honest. I don't think it's a black-white-Oriental thing. I think it's about the ability you have to get certain insurances. And what I have learned is that anybody who has insurance, personal insurance and they pay it, I think they will get a kidney quicker....

*Quicker than what?*

Quicker than a person that's on disability or on Medicare and Medicaid and the reason being that a private insurance company is going to look at it like this....we been paying for him to be dialyzing for thirteen years, and then when he get a kidney it's going to cost us another hundred thousand to get that kidney placed into him and to make sure he has the medication. A private company is going to think like that but the government has lost control so much with the medical and health part. You bill the government and they don't question it- it gets paid. They constantly putting that money out.

The private insurance company is going to be on the phone saying why isn't my patient ready for transplant because we're paying 7 thousand dollars for every (dialysis) treatment. When we going to get that kidney? The non private insurance company is paying for dialysis for thirteen years and on the fourteenth year for the kidney transplant. Then after that you got to pay for the person to get medication for the rest of their lives. There's some good and bad in everything.

*Do you have any religious of faith based beliefs.....*

No, but a lot of people do. I have some people in my family who do. They don't understand how I allowed them to give me two pints of blood.

*Do you think that getting a transplant is in any way an experiment.....*

**No, uh millions all over the world has gotten a transplant. I don't think that's an experiment there.**

*Is there anything else...*

**It goes back to the educational part. I have had people in here who said that they did not want a transplant and I asked why. And they said people told them that they was giving people pig kidneys, monkey kidneys. I heard everything and I tried to tell them I heard on the news.....but you are not going to get on the kidney list at Baltimore City and they give you a pig kidney. It would cost them a lot of money...the institution would probably crumble. That ain't going to happen. It all goes back to ignorance about what people hear or talk about when they don't know what they are talking about.**

Sarah: Interview 1

*Intro statements; When did you first consider a transplant?*

**Um, mostly when they told me about it...when I went to class to learn about it, and then when I first found out that I had kidney disease. That's when I found out about transplant.**

*Were there classes here (in the dialysis unit) or was it before you came to the dialysis unit?*

**Before I came to the dialysis unit, when evaluating you for kidney disease.**

*Did they send you to a class before dialysis to find out about your options?*

**Um hum, and I liked that. You can go as many times as you want.**

*That is good.*

**Um hum. They mostly said the same things over but you could go and ask questions.**

*Uh huh. So you started thinking about it then; long before dialysis. How many times did you go to the class?*

**I went to the class three times, and one of the nurses talked to me and I asked her questions about the transplant. And, I signed up for it and they did a lot of tests.**

*Ok, so that was signing up for the transplant evaluation. Who actually referred you to the transplant center; was it someone here at the dialysis center or did you call?*

**No, when they told me that I had kidney disease, renal failure, they had me sign up to talk to the nurses and doctors and stuff and they, you know, gave me information about it.**

*So, that was the appointment? You did it here at Hopkins?*

**Yes**

*So did you have to wait long for an appointment?*

**No**

*Was there a family member or a friend that you talked to.....*

**Yes, my husband, my daughter, my girlfriend (a girlfriend of mine, her mother had renal failure) and she told me about it and I would talk to them about it. And then when my children found out that they could be tested to see if they could give me a kidney, so you know, they really got into it then.**

*Did they really? Did they get tested?*

**Yeah, but uh, two of my daughters they suffer with high blood pressure, and my grandson-I really didn't want him to get involved because I thought he was too young and at that time he was into basketball and stuff. So he still wanted to get tested. But when he got tested he had high blood pressure.**

*Oh my goodness.*

**So he couldn't give me a kidney.**

*High blood pressure often runs in families*

**Yes**

*And so does diabetes-that is the other major cause of kidney failure.*

**Um hum.**

**It really bothered me because everybody said "you had high blood pressure" ....but it didn't um, mess my kidney up. Sarcoid is what messed my kidney up.**

**Sarcoidosis**

*So tell me about your family's involvement in the decision. It sounds like they were supportive.*

**Yeah, they were very supportive. Like my husband he carries me everywhere that I need to go. We are separated, but he carries me everywhere. All I've got to do is pick up the phone. He brings me here every morning and he picks me up and he always says, like they called me one time and said they might have a kidney and I need to get up here to give a blood sample...and he helped me through it because I was getting my hopes built up. He really helps me a lot on my decisions.**

*That's great, and it sounds like even though you are separated you are still friends.*

**Um hum, we are close.**

*That's great.*

*What was your meeting with the transplant team like?*

**It was really nice. They um, they talk to you a lot.....anything you want to know....they talk to you a lot.**

*So, how did you think you were treated?*

**Good**

*Did you feel like you came away with enough information?*

**Yes**

*You had been to education classes about your kidney failure, but this was more focused on what you need to do to get a kidney and what it is like to have a kidney transplant?*

**Yes. And then they called you after they meet with you, a couple days later; to see if you have any questions and then they call, maybe a month later, you know.**

*So you are on the list now?*

**Um hum**

*How did it go getting all of your testing done and things like that?*

**It was good. It was a lot of testing, but it's good, you know because they go through everything with a fine tooth comb.**

*Did you expect that when you started out?*

**Yes, but the doctors, like you might forget their names but they give you a card.**

**You know, it's hard to remember all of the doctors that you have met. But they made me comfortable because they gave me cards. I had so many cards from the**

**doctors. And they make you aware of the nurses. They would call, and they gave you a card. You know, so couldn't forget nothing.**

*There is a lot of testing and a lot to be done.*

**Um hum. You get a heart doctor, a kidney doctor and every kind of doctor there is.**

*Did you do most of your testing at Baltimore City Hospital?*

**Yes. I started going out to Oceanview and then they realized I had all of the doctors here so they sent me back here.**

*Were there any concerns or questions that you didn't feel you could talk about?*

**No**

*So, how long have you been on the list? Do you know when you got put on the list?*

**When I first started. I've been on the list about, maybe about two and a half years.**

*Ok, and you have gotten one call to come in?*

**Yeah, I was surprised. I thought at first-what! Can you come up-I said Yeah! I was so surprised because I wasn't on it (the list) that long.**

*I wish you luck with that.*

**Thank you.**

*So, did you have to have additional testing once you were on the list- to update your testing?*

**Yeah, I think it's every six months, they might update and make sure everything is still OK. I don't mind that.**

*Good. For many people it is hard to coordinate all of those appointments with dialysis.*

*With dialysis you week is kind of full in a way.*

**My primary care doctor, if I have some tests that needs to be done, she usually schedules around my dialysis. I was supposed to have an appointment on the 13<sup>th</sup> and she said "you have dialysis; I'll see you next Monday". So, usually it's pretty good. Today I have to have some blood done at Orleans St. and she know I had to go on dialysis so she said "whenever you get off dialysis you come over here"...so that's good.**

*So what do you think about the change in your life when you get a transplant? What are your thoughts about getting a transplant?*

**I never really thought about it.**

*Why do you suppose that is?*

**Because I know it's so hard to get a transplant; if I get one I'll deal with it then. I'm not thinking it'll be next year or next week or anything like that.**

*Do you live far from here?*

**No. But it just feels like before you know it I'm coming back (to dialysis) and I get really frustrated.**

*You get frustrated about.....*

**That I'm back so fast.**

*That you don't have much time in between your treatments?*

**Um hum.**

**And this time it seems like it's being more hard.**

*This time meaning....*

**I was on dialysis before and then I was taken off because my kidney was working good. I was off for like a year and a half and then I started back on dialysis.**

*Do you tolerate it OK? What do you feel like when you get out of here?*

**Sometime I feel a little frustrated or I feel mad...and then I say at least I'm back on dialysis-I'm still here.**

*And you do have an option since you have gotten through the evaluation.*

**Yes.**

*So in terms of how many African Americans have kidney disease.....do you have any thoughts about that or thoughts about fairness of the health care system?*

**Oh, I never thought about it.**

**Long pause.....**

*If you have time now I will ask you some more of the questions (from the second interview). I am afraid you will get your transplant before I come back!*

**Patient laughs**

*Were there any parts of the evaluation that were difficult for you to accomplish?*

**No.**

*What are your thoughts about the kidney donor.....*

**Well, it's just mostly I was really concerned about, I seen a little boy when I went when they called me to come in for some blood testing when they thought they may have a kidney for me, and when I was waiting there was a little boy. And we be wondering if he be tested to see if the kidney be good for him. And you kind of wondering if I get it before he gets it I would rather give it to him because he looked sicker than I did. I want to tell them they can give it to him first and not me.**

*I guess what you are saying is the way organs or distributed...how are the decisions made and is it fair? And the whole transplant community has always been very concerned about that. There are people who would say that they would want children to go first. But there are a lot of other things to look at in terms of the match and how long people had waited, and who can best manage taking care of the kidney so that it will last a long time. I think that those are important things. People always want children to go first.*

**I don't know how to put it into words...not just children. I think if I see somebody who looks sicker than me, I would want them to have it faster than me no matter what. You know. So that's why I really don't think about...**

*When you are going to get it?*

**Um hum...or who most deserves it.**

*Organs are managed like scarce resources in this country and it's important because every one is a special gift and there is a shortage of them.*

**There was this nurse and she said that.....I had a stroke before and ever since then I don't remember a lot of stuff. If I don't hurry up and say it I forget.**

*I think that happens to all of us.*

*Do you have any religious or faith based beliefs.....*

**No.**

**That's what I was going to say.....when they asked me if I wanted to be a donor**  
*Do you mean on your license?*

**Yeah, because my daughter told me she was a donor. She said that you are moved up on the list if you are a donor.**

*Well, she is right in a way. If you put it on your card (your license) you would not move up on the list but if you actually donate a kidney and then lose the function of the other kidney, you would be placed higher on the list. For example even though we screen living donors very very carefully, it has happened that someone who donated a kidney ten, fifteen years ago to a brother could have kidney failure when he turns fifty or sixty. Those people who have actually given a kidney are given an additional benefit. But you don't get that if you put it on your license. The hope is everybody puts it on their license. Do you think that getting a transplant is in any way and experiement.....?*

**No**

*Have you known anyone who has had a transplant before?*

**No.**

*Do you have any further thoughts?*

Sarah: Interview 2

*Review of previous interview, transcribed.*

*Have they called you at all for a transplant? (this patient is already on the waiting list)*

**No**

*Have there been any changes in your evaluation testing or have you talked to the transplant center?*

**No**

*So tell me what's been going on in the last month?*

**Well, about the same. Everything is about the same.**

*Nothing changed except you didn't feel well on Tuesday (patient had missed a previous dialysis session due to illness)*

**It started Sunday, when I started feeling badly. To me, this is the first time I have ever missed a treatment, and I felt real bad Tuesday and Wednesday, so I said I was coming today if I had to crawl here. Cause I don't usually miss no kind of appointments.**

*So the last time we met, we talked about a lot of things. You told me that your ex-husband is really helpful in a lot of things like your transportation, and supportive of your health needs. That is something that is looked at when patients are evaluated for transplant. You need help to get to appointments. Have you thought any more about transplant since we last talked?*

**It just seem like sometimes you think about it happening, and then; like the first time they called I was really surprised. But since then, I think it's going to be hard to get a transplant. So many people on it. I didn't realize how many people had kidney failure. So much about people getting kidney transplants. Especially like if a family member want to try, and be tested, and like if a friend, you know. I tell them if they want to be tested go ahead and be tested, even if it might not be a match, you know, for me, it might be a match for somebody else.**

*Explanation of the exchange program.*

**I didn't know that. That is good.**

*Have you talked to anybody or asked anybody about being a donor?*

**Uh huh.**

*How does that go for you? How do you bring it up?*

**Well, usually my friends, or family members, they want to know about it. And so we get to talking about it. And I've got these two tapes and they borrow the tapes and look at it, and a booklet they would read about it. That wasn't hard.**

*So you had some information to give to them.*

**Um huh.**

**And then I've got a girlfriend, I said before, that her mother had it. She told me a lot about it. And she would get information off the computer, you know.**

*You can get a lot on the computer today. Did your family members get tested and they weren't able to be donors?*

**Right.**

*Do you have any more thoughts about getting the kidney? We talked about your concerns before.*

**Oh yeah, especially I think that children or somebody that is more sicker than I am, like they can't or might not live long or don't want to be on dialysis or they've been on it longer than I have.**

*Once you are on the list, you move up on the list the longer you wait. There are people who are on dialysis for years who didn't get on the list. There have to be ways to make it fair, and that is hard. Children get more points than adults, so there is a belief that children should get priority. But it's not perfect.*

*Do you think it sounds fair?*

**Uh huh.**

*Do you think it sounds fair for African Americans and whites equally?*

**To me, if they weren't fair, you would know it. It's like if you were on the list before me, you would move up sooner than me.**

*Do you have any faith based or religious beliefs.....*

**No**

*Have you heard that anyone does?*

**No**

*Do you think that getting a transplant is in any way an experiment or that it is not proven to be effective?*

**No. I know one lady, she got a kidney transplant and she got the kidney for like eleven years, and then they went bad. And she, her sister give her another one.**

*How is she now?*

**She is good, but she drinks a lot. And I said, hey..you are messing up a good kidney. You can't change everything about everybody. Do you think that had something to do with her losing the first kidney?**

**Yeah, because she used to drink a lot. Like every day and I said, but she said 'you don't know what a person going through' which is true, but if she knows what I am going through coming to dialysis three times a week, what could be as bad as that. It seems to me that that 9her kidney transplant) is helping you out a lot.**



*People use a lot of different coping mechanisms and unfortunately alcohol is one of them that is used a lot. It doesn't directly damage the kidney but it might interfere with the medicines that they take, or their remembering to take the medicines if they are drunk.*

**Uh huh.**

*Is there anything else, or other thoughts? Long pause.....*

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## CURRICULUM VITAE

Susan Humphreys received a diploma in nursing from Mt. Auburn Hospital in Cambridge, Massachusetts, a Bachelor of Science in Nursing from Boston University in Boston, Massachusetts, and a Master of Science in Nursing with a focus on Nursing Administration, from Boston University.

She began her career as a critical care nurse at the New England Medical Center in Boston, Massachusetts. While raising three children, Ms. Humphreys worked in critical care and nursing education. Upon completing her Master's degree, she became a Nurse Manager at the Massachusetts General Hospital, and has remained in the field of solid organ transplantation ever since. Currently, Ms. Humphreys is employed at the Johns Hopkins Hospital Comprehensive Transplant Center.

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