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Perceptions Of Sexuality By African American Patients On Hemodialysis

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**PERCEPTIONS OF SEXUALITY BY AFRICAN AMERICAN PATIENTS ON
HEMODIALYSIS**

by

MERRY STEWART

DISSERTATION

Submitted to the Graduate School

of Wayne State University

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

2010

MAJOR: NURSING

Approved by:

Advisor

Date

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DEDICATION

This dissertation is dedicated to my family, fellow students, and friends who supported me, as I progressed through this stage of my life. I give special thanks to my husband, Willis Stewart for his love, patience, and understanding throughout this process. I thank God for sustaining me through the trials and giving me encouragement through the triumphs associated with earning a doctoral degree.

ACKNOWLEDGEMENTS

I am grateful to many people for all the love, support, and prayers granted me throughout my graduate studies. To my dissertation committee: I thank each and every one of you for your time, patience, and advice. Dr. Ramona Benkert, my advisor and chairperson has supported, directed, and encouraged me from my entry into the graduate program. Dr. Karen Aroian was instrumental in stimulating my excitement about exploring the meanings of individual experiences using a qualitative research design. Dr. Olivia Washington shared her qualitative research experiences and took the time to provide supportive feedback on my research efforts. Dr. Heather Dillaway shared her expertise and references related to social-related research and the study of sexuality.

I thank Dr. James Sondheimer for his unwavering support during the participant recruitment process and for sharing his expertise regarding people experiencing hemodialysis treatment. I also thank Dr. Rosalind Peters for encouraging me to increase my depth of understanding of theories and theoretical concepts. My sincere thanks to fellow students, Barbara Holley and Will Smith, for reviewing transcripts and helping to code themes associated with this research. I am grateful for their assistance that has contributed to the successful completion of this project. I appreciate Tonya Jones for her timely completion of my written transcripts and June Cline for her editing support.

Additionally, I want to acknowledge the funding support from the American Nephrology Nursing Association toward the progress and completion of this project.

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CHAPTER ONE

BACKGROUND

Defining the sexual self is central to the fundamental question asked by all humans, “Who am I?” (Nye, 1999). Sexuality incorporates more than the physical sex act and is acknowledged to be a complex and subjective concept that changes over time and must be understood from the perspective of each individual (Krozy, 2004). Sexuality may be particularly altered for the individual during experiences of chronic illnesses and associated treatments. Chronic illnesses and their associated treatments are suggested to not only interfere with physical and psychosocial sexuality, but also diminish one’s affirmation for life and connection with others (Krozy, 2004; Nusbaum, Hamilton, & Lenahan, 2003).

Expression of satisfaction with sexuality has been suggested to influence effective adaptation among those who are chronically ill (American Nurses Association [ANA], 2004; Burrows-Hudson & Prowant, 2005). In contrast, the experience of illness and altered sexuality is suggested to lead to a feeling of being betrayed by the body (Kralik, Koch, & Telford, 2001; Koch, Kralik, & Eastwood, 2002; Nusbaum, Hamilton, & Lenahan, 2003). A heightened sense of betrayal can lead to comparison of one’s sense of self to society’s construction of what constitutes being a man or woman. In addition, this comparison may result in a loss of man-or woman-hood if the individual is unable to reconcile the social identity of the labeled “me” with other social identities (Tepper, 1999). A diminished sense of self is suggested to lead to an alteration of one’s adaptive processes and to a loss of hope.

Perceptions of sexuality that diminish one’s sense of self may particularly be of concern for vulnerable populations. Vulnerable populations include those who are experiencing social, economical or situational disadvantages resulting in greater than average risk of developing health problems by virtue of their marginalized status (de Chesnay, 2005). Many African

Americans are among racial/ethnic groups who are likely to live at lower socioeconomic levels, be uninsured, and have poorer health than White people in the United States (U.S.). African Americans have also been denied rights associated with the traditional role of men and women through slavery and later institutionalized racism (Bowleg, 2004; Collins, 2005; Wyatt, 1997). This vulnerable population continues to experience limited economic and educational opportunities as compared to White American men and women (Bowleg, 2004; Wheary, 2006). These limitations may be perceived as additional barriers to assuming the traditional roles of men and women – thus further diminishing satisfaction with sexuality.

In addition, risk factors, such as incidence, morbidity, and mortality rates associated with chronic illnesses and injury, are disproportionately higher among African Americans than Whites (Center for Disease Control [CDC], 2005). These chronic illnesses include breast and prostate cancers, hypertension, diabetes, and end stage renal disease (ESRD) – all of which can result in higher incidences of altered physical and psychosocial sexuality identity (Krozy, 2004).

Perceptions, attitudes, experiences, and other psychosocial elements are suggested to have a greater association with one's sexuality and adaptive processes than physiological conditions (Gagliardi, 2002; Krozy, 2004; Perrett, 2007). For these reasons, African Americans' experiences and responses to perceived injustices are suggested to be related to the fundamental question of "who am I as men or women?" Information obtained from the exploration of African Americans' perceptions of sexuality may aid in understanding their coping processes and adaptive behaviors in response to chronic illnesses and treatments (e.g., end-stage renal disease and hemodialysis) for this vulnerable ethnic group.

Statement of the Problem

Despite recognizing sexuality as central to the individual's self-identity, frank discussions of sexuality in the U.S. continue to be considered taboo (Bullough & Bullough, 1995; Garcia,

1999; Nusbaum, et al., 2003). Bullough and Bullough (1995) indicated that most people in the U. S. today are heirs to Victorian and Graeco-Roman traditions and attitudes regarding sexuality. During the Victorian era, issues associated with sexuality were not viewed as proper for public discussion. Sex and discussions of sexuality outside of procreation were considered sins. These earlier views of sexuality continue to persist in society, even among health professionals who are charged with discussing such concerns with their patients (American Nurse Association [ANA], 2004; Bullough & Bullough, 1995; Burrows-Hudson & Prowant, 2005; Krozy, 2004).

Many health professionals admit to embarrassment and discomfort with addressing sexuality issues. Barriers to development of effective assessments and interventions related to sexuality include lack of knowledge and training (Gott, Galena, Hinchliff, & Elford, 2004; Haboubi & Lincoln, 2003; Katz, 2006; Magnan & Reynolds, 2006; Magnan, Reynolds, & Galvin, 2005; Rubin, 2005). Health professionals have described discomfort with addressing sexual issues with individuals of the opposite sex, different sexual orientations, and with people from other cultures (e.g., Black and other ethnic minority groups; Gott et al., 2004). Other findings indicated that patients wanted to discuss sexuality-related issues, but reported hesitancy unless health professionals initiated these discussions (Rubin, 2005; Waterhouse, 1996). Additionally, many nurses believed that they were not expected to inquire about their patients' sexual concerns (Magnan & Reynolds, 2006; Magnan, Reynolds, & Galvin, 2005).

Discussions and assessments of sexuality in a holistic framework are particularly relevant for people receiving dialysis therapy for end stage renal disease (ESRD) and for whom sexuality problems are commonly reported (Palmer, 2003; Sahin, et. al., 2004, Stewart, 2006). Dailey (1998) maintained that chronic illness and treatment, such ESRD and dialysis treatment, has a profound effect on ones' sexuality. Dailey further asserted that the expression of sexual feelings and needs in the context of a meaningful relationship may influence compliance with the dialysis

treatment regimen and with the individual's perception of hope. Consequently, assessment of sexuality within a holistic framework should address perceptions of physical functioning, personal identity, family-social roles as men or women, and intimate/personal relationships (Diemont et al., 2000; Rosas et al., 2001).

Roy (2009) suggested that perceptions inform about peoples' individual coping capacities. This view is similar to Dailey's (1998) observation that understanding perceptions of sexuality among patients on dialysis is relevant to development of effective assessments and treatment interventions. More effective assessments of sexuality are suggested to result in interventions that reduce emotional or physical setbacks in these patients.

A majority of research related to sexuality in individuals receiving dialysis therapy focuses on erectile dysfunction (ED) and associated treatments in men outside of the United States (Ali et al., 2005; Aslan et al., 2003; Naya et al. 2002; Rosas et al., 2003; Sahin et al., 2004; Stewart, 2006). Reports have also indicated a higher prevalence of sexuality-related problems for people receiving hemodialysis as compared to individuals who receive peritoneal dialysis, have had a kidney transplant, or for individuals who do not require dialysis treatment (Diemont et al., 2000; Katz, 2006; Rosas et al., 2001). Less is known about the psychosocial effects of hemodialysis on sexuality – particularly in African Americans who make up a disproportionate percentage of chronic hemodialysis patients (United States Renal Data Source [USRDS], 2009).

Addressing physical problems often is considered a "priority" for individuals receiving dialysis. However, psychosocial and cultural factors are suggested to be a primary cause of nonadaptive behaviors for these patients and are suggested to affect the sexual and relationship dimension for individuals receiving hemodialysis. Katz (2006) indicated that the prevalence of sexuality-related problems varies from 9% for people who are not on dialysis to 70% for individuals receiving dialysis.

A small number of quantitative studies have indicated that patients on hemodialysis infrequently report sexuality concerns to health professionals (Arslan et al., 2002; Milde, Hart, & Fearing, 1996). However, African American participants generally were under-represented in these studies. Published studies pertaining to African Americans' discussions of individual perceptions of sexuality since being on hemodialysis with either health professionals or their partners were not found.

Purpose of the Study

The purpose of this study was to explore perceptions of sexuality for African Americans who are experiencing hemodialysis for the treatment of end-stage renal disease (ESRD). The primary goal of the study was to understand the possible influence of chronic illnesses and treatments such as hemodialysis on perceptions of sexuality and on related adaptive psychosocial behaviors.

Specific Aim and Research Questions

The aim of this research is consistent with the American Nurses Association (ANA, 1974) and the American Nephrology Nurses Association (Burrows-Hudson & Prowant, 2005) standards of practice guidelines that support nursing interventions to assist patients with experiencing satisfaction with their sexuality. Roy (2009) maintained that environmental stimuli are filtered through one's perception that influences behavior and subsequent adaptation. Behaviors within any of the adaptive modes, as defined by Roy, may either influence or be influenced by perceptions of sexuality. For this study, a middle-range model with specific concepts related to holistic aspects of sexuality – the sexuality adaptation model (SAM) was derived from Roy's adaptation model and used as a guiding framework for this study. The specific aim of the study was to explore African Americans perceptions of sexuality since being on hemodialysis. The overarching research question was: What are African Americans

perceptions of sexuality since being on hemodialysis? The specific research questions developed for this study were:

1. What are African Americans' perceptions of physical sexuality since being on hemodialysis?
2. What are African Americans' perceptions of personal sexuality identity since being on hemodialysis?
3. What are African Americans' perceptions of family-social roles as men or women since being on hemodialysis?
4. What are African Americans' perceptions of intimate/personal relationships since being on hemodialysis?

Definition of Terms

African American(s)/Black(s): This term refers to people who self-identify with African ancestors. Both the term Black and African American will be used interchangeably in this study. The use of either of these terms will also be used in relevance to a particular time period or to particular topic.

Cool pose: Refers to a coping strategy used by males within the Black urban culture to adapt to environmental conditions of racism and socio-economic barriers.

Hemodialysis: One of the primary treatments of end-stage renal disease. Hemodialysis is a procedure in which a special filtering process removes waste and extra fluids from the blood via a vascular access. The hemodialysis regimen usually consists of treatment in an outpatient center three days a week for a period of 3 to 5 hours each visit. Dialysis treatment is considered as a lifetime procedure until kidney function is replaced by an effective kidney transplant.

End stage renal disease (ESRD): Chronic kidney disease that has progressed to the degree that dialysis (or transplantation) is necessary to maintain life.

Perception(s): Impression or understanding based on individual observations, thoughts, or emotions; means by which individuals interpret stimuli.

Sexuality: Appearance, feelings, desires, and expressions associated with holistic perspective of being male or female including physical sexual functioning, self-identity, family-social roles as men or women, and intimate relationships.

Traditional femininity ideology: Refers to a system of beliefs that women's lives are fulfilled by selfless roles as nurturers and caregivers in society as compared to more powerful and strong men.

Traditional masculinity ideology: Refers to beliefs about the importance of men adhering to culturally defined standards of male behaviors such as strong independent providers for family and community.

Vulnerable population: Refers to people who are experiencing social, economical or situational disadvantages resulting in greater than average risk of developing health problems by virtue of their marginalized status

Theoretical Framework

Middle-range sexuality adaptation model. A middle-range nursing theory of sexuality adaptation was used in this study to enhance understanding of the effect of the hemodialysis regimen on sexuality (i.e., physical sexuality, personal sexuality identity, family-social roles as men or women, and intimate/personal relationships). Middle-range nursing theories are identified as containing a limited number of concepts, relational statements, and propositions (Fawcett, 1999; 2005; Walker & Avant, 2005).

A diagram of the SAM (see Figure 1) reflects the middle range nursing theory developed for this study. This middle-range theory was deductively derived from Roy's adaptation model ([RAM]; Fawcett, 1999; Roy, 2009; Roy & Anderson, 1999; Walker & Avant, 2005). RAM

(Roy, 2009; Roy & Andrews, 1999) provides a framework to explore individual perceptions of sexuality and adaptive behaviors. The philosophical assumptions of RAM are suggested to be congruent with qualitative research which seeks to understand the subjective experience of individuals and (Perrett, 2007).

Theoretical overview of the Roy adaptation model. RAM is identified as both a grand nursing theory (Walker & Avant, 2005) and a conceptual model (Roy, 2009; Roy & Andrews, 1999; Fawcett, 2005). RAM reflects the reciprocal interactive worldview that identifies humans as active (in a constant process of change) holistic beings who interact with the environment in a reciprocal manner (Fawcett, 2005). Roy (1999; 2009) credited von Bertalanffy's general systems theory and Helson's adaptation-level theory as the basis for the scientific underpinnings of the RAM. Scientific assumptions of Roy's (2009) model were updated for the 21st century to include beliefs that:

1. consciousness and meaning are comprised of the integration between person and environment,
2. awareness of self and environment is embedded in thinking and feeling,
3. human decisions are responsible for the integration of creative processes,
4. human actions are mediated by thinking and feeling,
5. person and environment transformations are created in human consciousness,
6. adaptation is a process of the integration of human and environment meanings.

The philosophical assumptions of the model are associated with humanism and veritivity. Roy (1997) defined humanism as a movement "that recognizes the person and subjective dimensions of the human experience as central to knowing and valuing ..." (p. 6). Roy further defined humanism as based on the belief that humans possess creative power, behave purposefully, and are holistic beings who work to maintain integrity. Veritivity is a term coined

by Roy and refers to the affirmation of human existence for a common purpose (i.e., all humans strive for meaning and value in life). Roy's philosophical assumptions for the 21st century include the following assumption: "persons use human creative abilities of awareness, enlightenment, and faith; and persons are accountable for the processes of deriving, sustaining, and transforming the universe" (1997, p. 45). Another philosophical assumption underlying the RAM relevant to a holistic definition of sexuality is that "humans . . . strive to maintain integrity and to realize the need for relationships" (Roy & Andrews, 1999, p. 34).

Roy identified humans as adaptive systems who use conscious awareness and choice or coping processes to create human and environmental integration (Roy, 2009; Roy & Andrews, 1999). The environment, according to Roy and Andrews, consists of all conditions, circumstances, and influences that surround and affect the development and behavior of humans. Health is identified as a state and process of being and becoming whole and integrated and is reflected by adaptive responses. Nursing is viewed as being integral to facilitating human adaptive responses, thus contributing to health, quality of life, or death with dignity. Adaptive responses are identified as those that promote goals of integrity that includes survival and self-mastery. Ineffective responses do not contribute to this goal.

Roy identified four adaptive modes (physiological, self-concept, role function, and interdependence) that are defined as ways of manifesting adaptive processes or behaviors. Any of these modes alone, or in combination, can influence or be influenced by sexuality changes or concerns.

The physiological mode is associated with the physical and chemical processes of living organisms. The underlying need in this mode is physiologic integrity (Roy, 2009; Roy & Andrews, 1999). The other three modes are classified as psychosocial modes. The first of the psychosocial modes, the self-concept mode pertains to the personal aspect of the human system

or the “need to know who one is so one can be or exist with a sense of unity, meaning and purposefulness...” (Roy & Andrews, 1999, p.107). Roy divided the self-concept mode into two components – the physical self and the personal self. According to Roy, the physical self includes physical attributes and functioning. This mode is of primary importance in the promotion of adaptation. The personal self is defined by Roy as the individuals’ appraisal of one’s characteristics, expectations, values, and self-worth. The personal self component includes self-consistency, self-ideal, and the moral-ethical-spiritual self. The role function mode refers specifically to the place that a person holds in society and how the person acts in multiple roles. The underlying need in the role function mode is social integrity or “the need to know who one is in relation to others so that one can act” (Roy & Andrews, 1999, p. 110). The interdependence mode focuses on intimate and supportive relationships. The basic need in this mode is relational integrity or “the feeling of security in relationships” (Roy & Andrews, 1999, p. 112).

The environmental or input stimuli that affect the human system are described as focal, contextual, and residual (Roy, 2009; Roy & Andrews, 1999). Focal stimuli are defined as either internal or external stimuli that confront a person immediately. Contextual stimuli are the stimuli that contribute to the effects of the focal stimuli (e.g., age). Residual stimuli are described as the stimuli that have an undetermined or unclear effect on one’s behavior. For example, Roy and Andrews (1991) noted that residual stimuli can become focal if confirmed by the participant or if validated by theoretical or experiential knowledge. The complex dynamics relevant to human interaction and response to environmental stimuli are conceptualized by the RAM as coping processes.

Roy (2009) conceptualized the coping processes into two broad categories, the regulator subsystem and the cognator subsystem. The regulator subsystem responds by innate coping processes that involve the neural, chemical, and endocrine systems. The regulator processes are

viewed as automatic system responses. Coping processes within the cognator subsystem respond through an individual's cognitive-emotive channels that are identified as: perceptual/information processing, learning, judgment, and emotion channels.

Processes of both the regulator and cognator subsystems interact holistically to maintain and foster adaptation. Adaptive levels pertain to levels of response to stimuli. Adaptive levels are influenced by internal resources and demands of the situation. Three levels of adaptation (integrated, compensatory, and compromised) are identified within the RAM (Roy, 2009; Roy & Andrews, 1999). Integrated life processes are considered to be the most positive indicators of adaptive levels. Roy and Andrews defined this adaptive level as being one in which the structure and functions are working as a whole to meet human needs. The compensatory adaptive level represents activation of the cognator and/or regulator subsystems in response to a challenge to the integrated life processes. Processes related to personal loss (e.g., grieving) and sources of continued tension (e.g., difficult decision making) exemplify compensatory adaptive processes. Nursing facilitation of patients' adaptive responses are suggested to be particularly beneficial during this time to prevent or delay a compromised adaptive level. Compromised adaptive levels reflect inadequate integrated and ineffective compensatory life processes.

Development of the Sexuality Adaptation Model (SAM). Middle range theories address more concrete phenomenon and may be descriptive, explanatory, or predictive (Fawcett, 2005). Descriptive middle range theories are described as important for identifying "commonalities found in observations of individuals, groups, situations or events" (Fawcett, 2005, p. 19). A descriptive middle range nursing theory of sexuality adaptation was used to help generate the development of descriptive themes related to coping processes and behavioral responses of individuals' sexuality states associated with the hemodialysis regimen (Fawcett, 1999).

Concepts and propositional relationships from scientific and philosophical assumptions of the RAM (Roy, 2009; Roy & Andrews, 1999) were used to develop the SAM. The application of this middle-range theoretical model assists in offering plausible descriptions of commonalities of perceptions of sexuality among African Americans who are receiving hemodialysis treatment. Data gathered by semi-structured interviews are suggested to aid in establishing a basis for development of testable strategies and interventions related to experiences of altered sexuality by chronically ill patient being treated with dialysis (Walker & Avant, 2005). The explicit theoretical assumptions of the SAM are:

1. Sexuality is an aspect of overall well-being.
2. Sexuality is more than physical sexual functioning.
3. Sexuality includes the sexual and relationship dimension of the human condition.
4. Sexuality encompasses personal thoughts and feelings.
5. Sexuality encompasses attractiveness, sensuality, pleasure and pleasuring, intimacy, trust, communication, love and affection, affirmation of one's masculinity or femininity, and reverence for life.
6. Sexuality is influenced by contextual biological, psychological, social, and experiential factors.
7. Sexuality is an affirmation of life associated with one's connection or closeness with others.
8. Sexuality (e.g., a person's vitality, physical attractiveness, social interactions, etc.) can be disrupted by chronic illnesses or treatments – thus promoting distance in relationships.
9. Sexuality adaptation is the process whereby individuals express satisfaction with their sexuality.

10. Sexuality adaptation is associated with hopefulness, which is an important factor for positive adaptation.

Theoretical substruction (see Figure 1) reflects deduction of the abstract theoretical concepts of the SAM from the RAM. The vertical configurations of the substruction diagram represent the descending level of concepts abstracted from the RAM - stimuli, coping processes, adaptive modes, and adaptive levels. The theoretical concepts of the SAM are linked to empirical indicators that comprise the operational system. This process provides a logical and consistent connection between the theoretical and operational systems (Dulock & Holzemer, 1990; McQuiston & Campbell, 1996).

Stimuli. The theoretical concept, *sexuality state*, is used in the SAM as a label for the focal stimuli that most influences individuals' construction of their sexuality. The assessment of sexuality and contributing stimuli (i.e., contextual and residual) that trigger coping processes and adaptive responses are fundamental aspects of holistic nursing (Warner, Rowe, & Whipple, 1999). Sexuality is a basic dimension of every individual's personality and is influenced by biological, psychological, social, and experiential factors (Krozy, 2004). Ineffective sexuality responses can occur either in association with or lead to changes in physical sexual functioning, personal identity and body image, family-social roles as men or women, and intimate/personal relationship patterns. The assessments of individuals' sexuality is important and should include an evaluation of effects of focal, contextual, and residual stimuli on coping processes and adaptive responses.

The hemodialysis regimen is depicted as one of the most immediate stressors for individuals receiving dialysis and is identified as stimuli that alter or enhance the sexuality state for individuals receiving chronic dialysis. This regimen includes social isolation due to the need to spend extensive hours in the dialysis center, as well as mental, body image, and other physical

changes associated with the hemodialysis regimen (Burns, 2004). Perceptions of these focal stimuli are being empirically determined by data obtained from the demographic, health and sexuality relationship history, as well as the sexuality interview.

The contextual stimuli identified in the SAM is represented by established factors that contribute to the focal stimuli. Operational indicators of contextual stimuli associated with the hemodialysis regimen include personal demographics (e.g., age, gender, etc.), medical history (e.g., number of months/years on dialysis, etc.) and sexuality relationship history. Empirical indicators of the contextual stimuli are represented by descriptions on the demographic, medical and sexuality relationship history form, and responses to the sexuality interview.

Residual stimuli are represented by indeterminate historical, sociocultural, religious, and ethical influences and values that are perceived to alter or enhance one's sexuality. Events or situations that have unique meanings for, and influences on, individuals may lead them to identify seemingly contextual and/or residual stimuli as focal stimuli.

Coping processes. The most vital and fundamental aspects of individuals, according to Roy (2009) are perceptions of one's self. Roy's viewpoints are supported by previous quantitative research (Dahlen, 1980). Dahlen indicated that perceptions of an event can be a stronger indicator of adaptation than the actual triggering stimuli. An individual's perceptions are important aspects of the cognator subsystem and are a primary focus of this qualitative study.

The cognitive-emotive channels (i.e., perceptions and information processing, learning, judgment, and emotion) are operationally defined as sexuality coping processes in the SAM. Sexuality coping processes involve activities that are related to one's perceptions and identity of themselves as sexual beings (Binik & Mah, 1994; Dailey, 1998; Krozy, 2004).

Krozy (2004) stated that sexuality is intrinsically tied to personal feelings and thoughts. Binik and Mah (1994) suggested that questions regarding sexuality give permission to the patient

to discuss the topic openly and relate his/her feelings, thoughts, and intentions. Patton (2002) stated that personal interviews “begin with the assumption that the perspective of others is meaningful, knowable, and able to be made explicit” (p. 341). A semi-structured sexuality interview guide was developed for the present study to help facilitate participants’ responses related to perceptions of their sexuality.

Adaptive modes. The evaluation of both physiological and psychosocial sexuality adaptive modes is an important domain for nursing practice (American Nurses Association [ANA], 2004; Krozy, 2004; Magnan, Reynolds, & Galvin, 2005). This process requires more than understanding the physiological issues related to diseases. For example, erectile dysfunction as previously indicated, is the physiological condition most often associated with sexuality in male dialysis patients. However, the pain and confusion of real-life experiences are not captured by the knowledge that a given number of men struggle with ERS (Dailey, 1998). Dailey (1998) and Krozy (2004) maintain that it is important to recognize the potential effect of emotional reactions, and real life sexuality and relationship concerns on adjustment to one’s illnesses.

The middle-range theoretical concepts for this study were: physical sexuality, personal sexuality identity, family-social roles as men or women, and intimate/personal relationships. Physical sexuality is associated with the physiological adaptive mode and was characterized by physical sexual behaviors identified by participants since being on dialysis. An individual’s personal sexuality identity includes self-identity and body image that is associated with the self-concept mode. The identity of one’s sexuality well-being (e.g., body image and/or self-identity as men or women) reflected adaptive responses in the personal sexuality identity mode. Family-social roles related to one’s position in their family and to society in general were associated with the role function mode. The theoretical concept identifying this mode is the family-social role adaptive mode. Behaviors reflective of the family-social role function mode included an

individual's identity of family and social roles as men or women since being on dialysis. Evaluation of the intimate/personal identity mode is of particular importance in the assessment of sexuality. This mode included the identity of an individual's intimate or personal relationships (e.g., pattern and level of satisfaction with meaningful relationships with others). As indicated previously, Dailey (1998) maintains that the "ability to express sexual feelings and needs, especially in the context of a meaningful relationship, might impact chronic illness itself" (p. 81). Behaviors reflective of the interdependence role included expressions related to the effect of the hemodialysis regimen on intimate and personal relationships.

Adaptive levels. Specific identity of psychosocial adaptive levels was not a focus of this qualitative study, but was suggested to be identified as follows. Expressions that indicate satisfaction with one's sexuality suggests an integrated adaptive level. A compensatory adaptive level can be reflected by expressions of sexuality disturbances, but not an absolute loss of sexual identity as men or women. Compromised adaptive levels can be inferred by expressions of either the loss of or altered sexuality.

Summary. The input or focal stimuli indicated on the SAM include variables related to the hemodialysis regimen and sexuality state as the confronting stimuli. These input stimuli also include contextual and residual stimuli that are reflected by the personal demographics; medical and sexuality relationship history; and perceptions of historical, socio-cultural, religious, and ethical factors. Self-perceptions are linked intrinsically to one's sexuality and are identified as important aspects of the cognator subsystem. Four cognitive-emotive channels (see Figure 1) are associated with the cognator subsystem and are instrumental to development of sexuality coping strategies. Human responses related to physical sexuality, personal sexuality identity, family-social roles as men or women, and intimate/personal relationships reflect the adaptive modes and

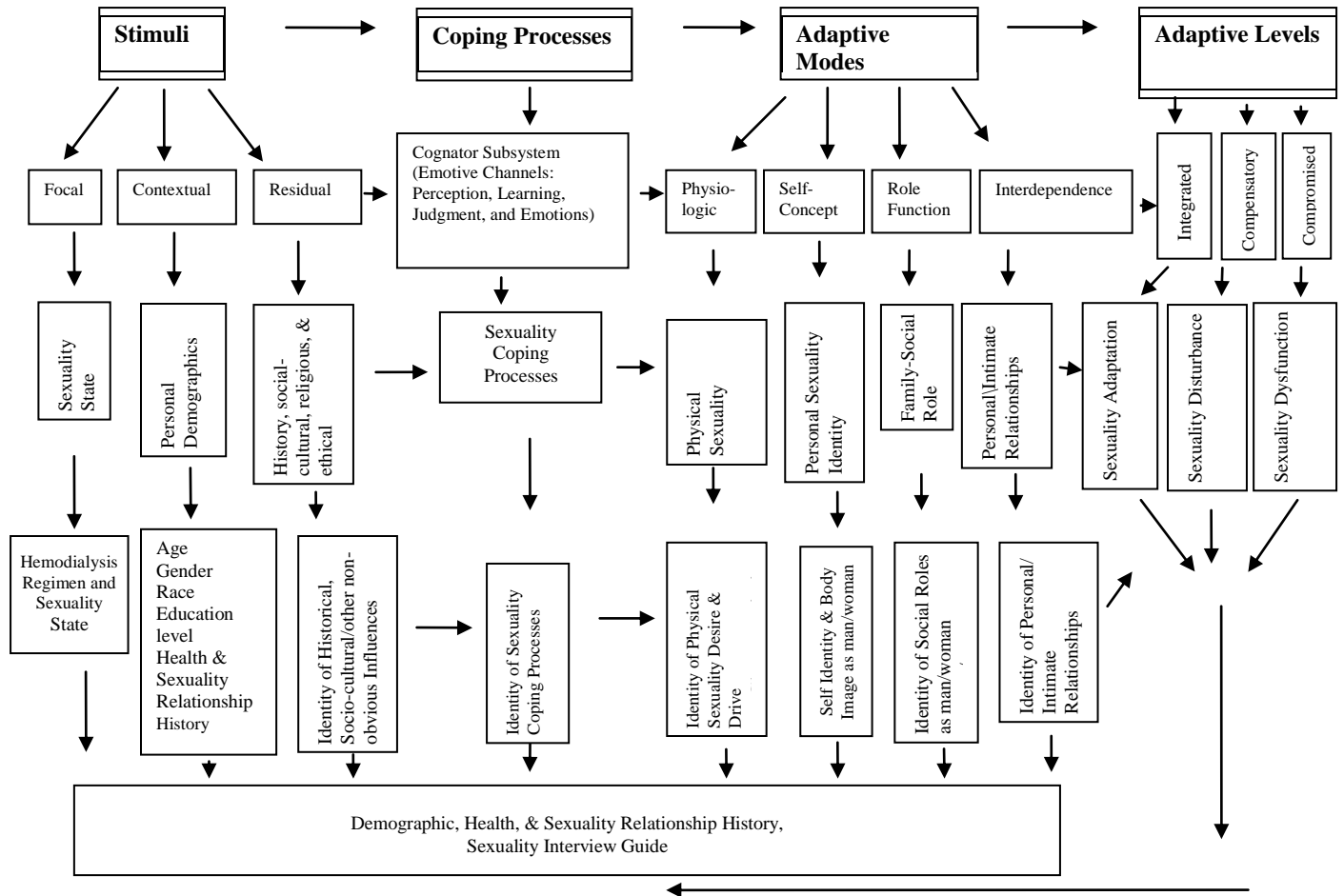


Figure 1. Pictorial Representation of Derived Model – Sexuality Adaptation Model

are empirically represented by verbal responses to a demographic, health and sexuality relationship history, and sexuality semi-structured interview. This middle-range theory is congruent with the reciprocal interaction world view. The sexuality adaptation model also provides a relatively concrete and specific structure for interpretation of perceptions of sexuality within a holistic framework (Fawcett, 2005).

Purpose of the Study and Theoretical Assumptions

The purpose of this study was to explore perceptions of sexuality for African Americans who are experiencing hemodialysis therapy. An overall goal of the study was to understand perceptions of physical sexuality, personal sexuality identity, family-social roles as men or

women, and intimate/personal relationships associated with the hemodialysis regimen. Findings from this study may aid the development of strategies to improve assessment and management of hemodialysis-associated sexuality problems. Findings may facilitate understanding of the possible influence that perceptions of one's sexuality has on adaptive psychosocial behaviors (e.g., effective communication with health professionals).

Significance to Nursing

Standards of care that support individuals' expression of satisfaction of sexuality have been identified by the ANA since 1974. Sexuality-related standards of nursing care are now included in a number of nursing specialty practice organizations, including the ANNA (Brennon, Burrows-Hudson, Day, & Libonate, 1988). ANNA's standards and guidelines for nursing care of the nephrology patient stated that "sexuality is a human experience that needs to be explored, experienced, and shared" (Burrows-Hudson & Prowant, 2005, p. 388). These standards emphasized the need for nurses to be prepared to address common sexuality problems in their practice.

Few studies have explored perceptions of effects of the hemodialysis regimen on sexuality. This qualitative study may provide new knowledge about African Americans' perceptions of sexuality while undergoing dialysis. New knowledge about the affects of hemodialysis on perceptions of sexuality is important to nurses who are responsible for promoting satisfaction with sexuality for individuals on hemodialysis.

CHAPTER TWO

Literature Review

This chapter presents an overview of end stage renal disease (ESRD) and hemodialysis related statistics for African Americans. A literature review of focal and contextual stimuli associated with the hemodialysis regimen and of its known effects on perceptions of sexuality will also be presented. Additionally, this chapter will include a review of historical and socio-cultural influences on constructions of sexuality for African Americans.

Overview: End Stage Renal Disease and African Americans

Irreversible chronic kidney failure refers to the inability of the kidneys to remove waste products or toxins from the body. When the level of kidney failure becomes life threatening, this condition is identified by the medical profession as ESRD. Based on 2007 data, the incidence rate (adjusted for age, gender, and race) of ESRD was 354 per million population in the U.S. (United States Renal Data Source Report [USRDS], 2009).

Racial disparities in ESRD incidence are dramatic. Point prevalence rates in 2007 for African Americans was 4.2 times greater than for whites (5,111 per million compared to 1,222 per million population) (USRDS, 2009). The point prevalence rate of ESRD among African Americans was also greater than that among Native Americans (2,713), Hispanics (2,408), and Asians (1,911). Incident rates (2007) were 273 and 998 per million population for whites and African Americans, respectively (USRDS). Rates of ESRD tend to be highest in metropolitan areas. The following cities were among those for which prevalence rates for African Americans ranged from 4,000 to 7,000 per million population: Chicago, Cincinnati, Cleveland, Dallas-Fort Worth, Denver, Detroit, Houston, and St. Louis.

According to the 2009 USRDS report, the 2007 incidence rate for males was 1.2 times higher than the number of females. The median age of incidence for populations experiencing

ESRD was reported to be 64.4 years. The median age for African Americans was 59.1 years as compared to 64.4 among whites. However, younger African American men ages 25 to 44 have been reported to be up to 20 times more likely to develop kidney failure than Whites (National Institutes of Health, 2004).

Diabetes and hypertension continue to be identified as the primary causes of ESRD (USRDS, 2009). In 2007, diabetes accounted for approximately 54% of new ESRD cases and one in three new cases was caused by hypertension. The incidence rate for ESRD due to diabetes was approximately 3 times higher for African Americans than for Whites.

Hemodialysis Statistics for African Americans

Two types of treatments are offered for ESRD patients in order to sustain life – dialysis or kidney transplantation. Kidney transplantation is the ideal treatment for ESRD. However kidneys are not readily available for transplant and not all ESRD patients are acceptable or willing candidates for kidney transplants. The prevalent population waiting to receive a transplant has increased from 9,447 in 1988 to 73,555 in 2007 (USRDS, 2009). The incidence rate among African Americans for transplant in 2007 was 5.7 % per million compared to 7.5% for Whites.

Dialysis is a permanent treatment for ESRD unless a kidney transplant or recovery of function occurs, which happens in less than 5% of patients (attending nephrologist, personal communication, December 29, 2009). According to the latest USRDS report (2009), 368,544 patients were receiving dialysis treatment for the treatment of ESRD. The two types of dialysis are hemodialysis and peritoneal dialysis. Only hemodialysis will be reviewed for the purpose of this study.

Hemodialysis utilizes a machine to remove waste products from the blood and is usually performed in hospitals or outpatient dialysis centers. Patients on hemodialysis made up

approximately 93% of the total number of patients on dialysis in 2007 (USRDS, 2009). The prevalence of African Americans on hemodialysis is reported to be six times greater than whites and nearly two times greater than Native Americans.

Demands, Coping Processes and Behaviors Associated with the Hemodialysis Regimen

The demands of chronic hemodialysis on people are considered to be the most stressful of all illnesses and treatment regimens (Burns, 2004; Cinar, Barlas, & Alpar, 2009). According to Burns (2004), these individuals focus on dialysis as an illness rather than on the specific effects of ESRD alone. The hemodialysis regimen is suggested therefore to influence the construction of sexuality for individuals on hemodialysis. However, published studies that have explored these individuals' perceptions of personal sexuality identity, family-social roles as men or women, and intimate/personal relationships were not found. Therefore, despite the high incidence of African Americans receiving hemodialysis, this population is minimally represented in previous published studies focused on the association of hemodialysis and psychosocial aspects of sexuality.

Past studies of hemodialysis and sexuality have focused on commonly reported physical sexuality changes or concerns. These physical concerns included a significant incidence of erectile dysfunction or premature ejaculation in males (Ali et al., 2005; Aslan et al., 2003; Naya et al., 2002), decreased sexual satisfaction (Aslan et al., 2003); and sexual desire disorder (Camsari et al., 1999).

The psychosocial changes associated with hemodialysis include loss of time and lifestyle changes related to time spent in dialysis centers (i.e., a minimum of three to five hours, three days a week). Many individuals receive 8 hours or more of nocturnal or overnight dialysis treatment three days a week to minimize complications associated with unwanted rapid blood flow rates that can occur during hemodialysis (Davita, 2007). Other physical and psychosocial

changes and concerns associated with hemodialysis include frequent arterial and venous punctures skin pigmentation and appearance changes, physical mobility limitations, food and fluid restrictions, fatigue, cost of care, family role alterations, and feelings of inadequacy (Burns, 2004; Tsay, Lee, & Lee, 2005).

An individual's response to the hemodialysis regimen is processed through past learning experiences, perceptions, problem-solving and decision-making processes and emotions (i.e., coping processes). Stimuli associated with the hemodialysis regimen often triggers perceptions of social isolation and uncertainty due to periods of instability, and the time and effort required to regained stability (Pelletier-Hibbert, & Sohi, 2001; Ziegert & Gridlund, 2001). Responses to these perceptions are suggested to result in individual behaviors that reflect either effective or ineffective adaptive modes.

A small number of qualitative studies have identified psychosocial responses of females to the hemodialysis regimen. These studies included reports of altered body image and decreased sexual attractiveness for female patients (Rickus, 1987; Tanyi, 2002). Polaschek (2002) used a critical interpretative methodology to assess the living experiences of 20 Caucasian men (ages 20 to 60 years) on home hemodialysis. This New Zealand study did not focus on issues related to sexuality, but did indicate that the younger single males (n = 6) reported greater inability to sustain partner relationships (Polaschek, 2002). However, these qualitative studies did not focus on the multiple social identities from which sexuality is constructed.

Summary. The comprehensive hemodialysis regimen may be identified as confronting or focal stimuli for patients who are receiving this therapy. Facets of the hemodialysis regimen may also be identified as contextual or residual stimuli. Previous studies of sexuality and individuals receiving hemodialysis have primarily focused on physical sexuality responses in men. The participants of most previous studies were also noted to be citizens of countries other than the

United States. The present study sought to identify holistic perspectives of African American men and women's perceptions of sexuality since being on hemodialysis.

Historical and Socio-cultural Influences on the Construction of Sexuality

For African American Women

Constructions of sexuality differ for each individual and require an understanding of multiple social identities (Krozy, 2004; Tepper, 1999; Warner, Rowe, & Whipple, 1999). An awareness of factors that commonly influence construction of sexuality for a specific group of people is suggested to aid the development of appropriate assessment and intervention measures related to their perceptions of sexuality. A review of historical and socio-cultural factors that have contributed to the perceptions of sexuality for African Americans is relevant to understanding the needs of this vulnerable population.

Sexuality stereotypes – Black women. Sexuality stereotypes of Black women have emanated from their years of slavery in early America – years of being bought and sold and of having little or no control over their own bodies (Collins, 2005; Simms, 2001; Wyatt, 1997). Labels of jezebel, mule, and mammy were terms most often used to identify enslaved Black women (Collins, 2005; Simms, 2001; Wyatt, 1997). Simms asserted that these images were popularized and legitimized by southern White intellectuals. Simms' view was supported by research of historical literature written by pro-slavery apologists from 1787 to 1865. The findings of this research revealed that writings from this period in the areas of religion, natural science, popular literature, social science, politics, law, and philosophy greatly contributed to the controlling images and subordination of Black women, as well as current sexual stereotypes of this group.

Jezebel. A characteristic often attributed to African women during slavery was that of the sex starved Jezebel (Collins, 2005; Guy-Sheftall, 2002; Simms, 2001; Wyatt, 1997). This image

of enslaved Black women as childishly promiscuous and sexually aggressive was used to justify rapes and sanctioned their role as breeders. The image of Black women as jezebel is suggested to have persisted “in the Euro-American imagination long after slavery and colonialism has ended” (Guy-Sheftall, 2002, p. 16).

Such sexuality stereotypes of Black women as Jezebel continue to influence the construction of their sexuality. Collin (2005) stated that in the early 20th century, northern Black middle class women (i.e., women in Black Baptist churches and Black women’s clubs) sought to reform the image of Jezebel. Actions to reform the Jezebel image were guided by perceptions of Black women migrants from the south as socially dangerous. Northern women groups’ endorsement of respectability (e.g., characteristics of cleanliness of person and property, polite manners, and sexual purity) further influenced these reforms. According to Davis (1998), achieving such respectable standards was felt to be too restrictive and was subsequently rejected by many Black working class women in urban areas. Davis further suggested that the restrictions placed on individual sexuality for many working class Black women were associated with denial of freedom to define themselves. Rather than promote promiscuity, these women endeavored to reject bourgeois notions of sexual purity, as they sought to revise the image of mammy and jezebel in order to define and express their sensuality and sexuality in ways they deemed to be appropriate.

Mule. Enslaved women were most valued for their labor. Viewing these women as less than human or as mules justified beatings, being worked to death, and being treated as domestic stock (Simms, 2001; Wyatt, 1997). Simms asserts that religious teachings particularly reinforced the image of the African woman as a mule. Simms cited writings by Stringfellow (1799-1869), a noted religious leader who claimed that beating and working Black enslaved women to death was based on biblical authority.

Principles of sexual purity representative of the mule stereotype continue to persist for Black women who are employed in professional roles (Wyatt, 1997). Wyatt suggested that today's well-dressed single Black female executives project the image of the mule or workhorse. For these women the price of respectability or sexual purity has required rejecting or sacrificing their femininity in favor of being perceived as tough as any man.

Mammy. Many enslaved women survived by feigning dull-headed submission, complacency, and obedience to their masters and their families (Collins, 2005; Simms, 2001; Wyatt, 1997). The role of mammy positioned the slave woman neither a threat to her mistress nor a temptation to her master. This woman was considered asexual and therefore was at less risk for sexual abuse than other enslaved women.

The identity as mammy also is suggested to continue for Black women today as a method of coping with the stress of poverty and a manifestation of feeling unloved (Wyatt, 1997). This identity is ascribed to Black women who have assumed complacent roles associated with sedentary lifestyles and habits of overeating (Beauboeuf-Lafontent, 2003).

Sexual identities influenced by negative messages. Rouse-Arnett, Dilworth, and Stephens' (2005) findings supported the assertion that the Black women's sense of sexual identity continues to be influenced by such persistent negative messages as described above. These investigators examined the influence of social institutions (i.e., educational, religious, and healthcare institutions) on African American women's sexual values and attitudes. The nine participants in this study ranged in ages from 18 to 31 years ($M = 21.5$). They were recruited from an adult education project designed to improve the educational and economic opportunities of low-income women. The themes that emerged from this qualitative study included experiences of fear, silencing, and a loss of empowerment. They were based on negative experiences that the women associated with the social institutions identified above. Such

negative experiences are suggested to be internalized and to potentially affect individual sexuality.

The continued influence of negative sexuality images on Black women was further supported by a study of Black (n = 326) and White (n = 804) women's views of three domains of dominant femininity. These domains included: (a) feminine appearance (i.e., creating and maintaining a feminine appearance of body and home); (b) feminism as reflected by socially desired feminine traits (e.g., being gentle and sensitive), and (c) traditional gender role ideology based on assumptions about appropriateness and desirability of separate and well-defined roles for women and men (Cole & Zucker, 2007). The Black women in this study rated feminine appearance associated with clothing ($p < .001$) and home ($p < .001$) significantly higher than White women. These findings suggested that sexual purity continue to be associated with an external feminine appearance. Such physical and psychosocial stimuli associated with the hemodialysis regimen are suggested to be perceived as negative, thus potentially having a major effect on Black women's sexuality.

In contrast with White women, the Black women in Cole and Zucker's (2007) study were more likely to identify as feminists ($p < .001$). This finding was suggested to be associated with Black women having a greater sensitivity to experiences of racial and socioeconomic oppression than White women. These findings also suggested that Black women's constructions of sexuality are not limited to their identity as women, but also includes other social identities (i.e., specific roles as Black woman).

The unique integration of identities of woman in general and Black woman in particular, also was noted by Settles (2006). Settles surveyed Black women undergraduate (n = 60) and graduate students (n = 29) from 31 different universities in the U.S. to determine their perceptions of the importance of three identities as – woman, Black person, and Black woman.

Findings revealed that an intersection of identity as a Black woman was more important than the separate Black identity ($p < 0.10$) or woman identity ($p < 0.05$). This finding indicated that a Black woman's sexuality is not limited to the context of her gender, but includes her race as a significant aspect of her sexuality.

Summary. African American women are noted to particularly define their sexuality in relation to having a “respectable” appearance of clothing and homes. This response by African American women is suggested to be influenced by the historical subordination of Black women. This response is also suggested to be an attempt to fit within female roles that are acceptable to the White norm. However, the significance of the integration of identities of woman and Black as compared to a separate identity as Black or as a woman should be noted. Inner conflicts are suggested to occur as a result of the Black woman's comparison of herself to society's construction of what constitutes being a woman. This conflict may be perceived as negative stimuli by Black women and add to the confronting event. Negative experiences associated with social institutions (e.g., health care systems, religious and educational institutions including dialysis centers) are also suggested to represent negative focal, contextual and/or residual stimuli. Research that explores African American women's perceptions of their sexuality when confronted with comprehensive effects of chronic illness and treatments such as the hemodialysis regimen is relevant to understanding the needs of these individuals.

Historical and Social-Cultural Influences on the Construction of Sexuality for African American Males

Published studies pertaining to adult African American men and sexuality are less prevalent. Bowleg (2004) stated that the invisibility of adult Black men in research is puzzling given their historical and socio-culturally link to Black women. Enslavement for the Black man is reported to have been even more physically and emotionally taxing than the enslavement

experienced by Black women (Collins, 2005; Levant & Majors, 1997; Majors & Billson, 1992). Collins states that “harsh conditions forced upon Black men required objectifying their bodies as big, strong, and stupid” (p. 56). Black men were denied traditional masculine and patriarchal roles and powers that came with family and property (Collins, 2005; Levant & Majors, 1997). They were forced often to witness violence against their female partners and children. Their identity as men was further restricted by their awareness of the White man’s ability to whip and kill them at will.

Sexuality stereotypes – Black men. The systematic denial of Black men’s rights to express traditional masculine role attributes of assertion, protection of family, and provider continued in the segregation period following the Civil War and emancipation (Collins, 2005; Levant & Majors, 1997; Levant, Majors, & Kelly, 1998). Markers of sexuality used to define enslaved African American men were associated with sexual prowess and brute strength (Collins, 2005). Collins stated that negative stereotyping or controlling images such as “buck” permitted perceptions of masculinity for Black men that most benefited Whites. The term buck defined a human animal that had achieved partial domestication through slavery. According to Collins, the representation of Black men as a buck reinforced the image of Black men as intellectually inferior to Whites. The buck image also reinforced the political status of the enslaved Black man as chattel.

Gains from the Civil Rights movement diminished some of the harsh restrictions for African American males. Nevertheless, economic, educational and occupational barriers to positive expressions of traditional male role behaviors or ideology for African American men has persisted (Bowleg, 2004; Collins, 2005; Levant & Majors, 1997). A persistent lack of opportunities on the same terms as White men continues to limit the potential achievement of

traditional masculinity for African American males (Levant & Majors, 1997; Levant, Majors & Kelly, 1998; Bowleg, 2004).

Adaptive strategies for African American males. African American males' perceptions of traditional male roles have been linked to an endorsement of traditional masculinity ideology (Levant. et al., 2003; Levant & Majors, 1997; Levant, Majors, & Kelley; 1998; Pleck, Sonesta, & Ku, 1993; Rose, Kim, Dennison, & Hill, 2000; Wade, 2008). Traditional masculinity ideology is a commonly used term that refers to “beliefs about the importance of men adhering to culturally defined standards of male behavior” (Pleck, Sonenstin, & Ku, 1993, p. 12). These belief systems are thought to vary among individuals and groups and may change over time (Addis & Mahalik, 2003; Coutenay, 2000).

Common characteristics of traditional masculinity ideology include being the supporter, being dependable and able to deal with adversity, being physically strong, taking pride in being able to perform sexually, and the general acceptance and encouragement of sexual promiscuity (Wade, 2008). Black men who endorse traditional masculinity are perceived as needing to preserve an image of being able to handle anything (Rose, Kim, Dennison, & Hill, 2000; Royster, Richmond, Eng, & Margolis, 2006). This image is suggested to be minimized by health and other concerns that imply being less than a man.

Levant and Majors (1997) examined perceptions of traditional masculine ideology among African American (n = 270) and European American (n = 226) men and women using the Male Role Norms Inventory (MRNI). Study findings supported the assertion that African American men place greater importance on traditional male roles, including providing for and taking care of their families. African American men also were found to have greater perceived barriers to the traditional male role. One form of adaptive response to this severe gender role strain among African American men has been identified as “*Cool Pose*” (Levant & Majors, p. 41).

“Cool pose” is identified as a coping strategy used to adapt to environmental conditions of racism and socio-economic barriers (Majors & Billson, 1992). “Cool pose” is particularly identified among males within the Black urban culture. Adaptive behaviors (e.g., assertive slang, aggressive posture, etc.) associated with “cool pose” have been criticized as negative and as a factor in Black underachievement (Osborne, 1999). However, Majors and Billson (1992) suggested that “cool pose” helps Black men neutralize stress caused by social oppression and racism. Additionally, they argued that “cool pose” provides a sense of control and confidence for Black men. This argument is supported by the higher scores on the Self-Reliance subscale of the MRNI by African American men. These higher MRNI scores are suggested to “reflect a cultural adaptation to the effects of persistent racism, in which African American men have come to believe that they are forced to rely on themselves to a greater extent than are other people” (p. 42).

A follow-up study by Levant, Majors, and Kelley (1998) compared the perceptions of African American and European men and women from universities in the Northeast and the Mid-Atlantic region to the participants from the Southern universities noted in Levant and Majors’ previous study (1997). Findings revealed that African American men from the South endorsed a more traditional view of masculine ideology than any of the other groups of men or women. Levant et al. (1998) stated that these findings indicate a need to evaluate the importance of subcultural variations (e.g., metropolitan vs. rural areas) within cultural groups defined by race. In addition, they suggested that ties to less traditional values and a greater influence by modern constructions of gender within the larger metropolitan environments of the Northeast and Mid-Atlantic region decrease adherence to traditional masculine norms.

Levant and Majors (1997) stated that a demonstration of “cool pose” also is reflected by the higher scores of African American men on the Non-relational Attitudes toward Sexuality

subscale of the MRNI. These scores are thought to represent sexual promiscuity among Black men as a way of demonstrating their manhood. Levant and Majors' further asserted that traditional masculine ideologies that encourage men to be sexually promiscuous were supported by Bowleg (2004).

Bowleg (2004) explored the influence of masculine ideologies on relationships, sex, HIV concerns, and condom use among African American men in heterosexual relationships. Thirteen men ranging in age from 24 to 50 years ($M = 34.62$, $SD = 7.96$) participated in this mixed method (i.e., qualitative and quantitative) study. Findings revealed generally positive portrayals of intimate relationships. Nine of the men reported monogamous relationships. However, participants also reported that male friends often encouraged multiple sex partners and recreational sex. These declarations were reported to suggest values that are consistent with the views of traditional masculinity ideologies.

Summary. The effects of historical, economic, and social oppression may represent either focal, contextual, and/or residual stimuli that continue to influence African American men's perceptions of sexuality. African American men are noted to strongly endorse traditional masculinity ideology. However, due to institutionalized racism, economic and educational barriers, many African American men are suggested to perceive limitations on their roles associated with traditional masculinity ideology. African American men are noted to use cultural adaptive strategies such as "cool pose" to guard against frustration caused by perceived limitations. Variations secondary to geographical locations are also suggested to influence the degree of endorsement of traditional masculinity attributes among African American men.

CHAPTER THREE

METHODS

The methods that were used to collect and analyze the data needed to address the research questions developed for this study are presented in this chapter. The topics included in the chapter are restatement of the problem, research design, and data analysis. Methodological problems will also be discussed as well as the strategies for addressing these problems.

Restatement of the Problem

This study explored African Americans' perceptions of physical sexuality, personal sexuality identity, family-social roles as men or women, and intimate/personal relationships since being on hemodialysis.

Research Design

A qualitative descriptive design was used in this study to provide an in-depth exploration of African Americans' perceptions of sexuality since being on dialysis. This design is used to study a phenomenon that is either unstudied or understudied in the specific population (Brink & Wood, 1998). The qualitative descriptive design also offers a comprehensive summary of the meaning of concepts in everyday terms used in association with a particular population (Sandelowski, 2000).

Consistent with descriptive exploratory designs, data were collected using semi-structured sexuality interviews. The Sexuality Adaptation Model (SAM) derived from Roy's Adaptation Model ([RAM] Roy, 2009; Roy & Andrews, 1991; 1999) was used as a guiding framework and provided focus for this qualitative study (Morse & Richards, 2002). Identification of focal, contextual, and residual stimuli (i.e., demographic variables including intimate/sexual relationship history and medical history), perceptions of sexuality since being on dialysis, and of the related adaptive behaviors were used to categorize emerging themes.

Establishing rigor. Rigor or trustworthiness of this research process and findings was established using the following criteria: credibility, transferability, dependability, and confirmability.

Credibility refers to an accurate portrayal of what is being studied (Guba & Lincoln, 1989; Miles & Huberman, 1994; Trochim, 2006). A thorough description of the research process that acknowledges the influence of both immediately confronting and contributing factors on perceptions of sexuality lends credibility to this study. Creating a sexuality interview based on a specific theoretical framework helped focus on the study goals and contributed to credible results. The completion of a pilot interview process to ensure effective solicitation of data related to a specific research aim and research questions also helped establish credibility. Additionally, research findings were reviewed by a nephrologist possessing extensive experience with hemodialysis centers and hemodialysis patients. This review provided an assessment of the accurate portrayal of data from individuals receiving hemodialysis therapy. Findings of this study are being reported that accurately portray perceptions of sexuality of participants since being on dialysis (Sandelowski & Barroso, 2002).

Transferability in a qualitative study refers to the ability to fully describe characteristics of the sample in a way that permits adequate comparisons to other samples (Miles & Huberman, 1994; Trochim, 2006). The maximum variation sampling strategy used in this study resulted in participants who had varied personal and hemodialysis-related demographics (e.g., gender, age, marital status, length of time on dialysis, sexual activity status, etc.). This sampling strategy facilitated the generalizability of the study's findings to other African Americans experiencing hemodialysis (Sandelowski, 1995). Additionally, the PI utilized a semi-structured interview guide to assist in eliciting rich responses to questions based on a specific research aim. The

presentation of broad descriptions of participants as an explanatory factor in the analysis of data further lends to transferability of this study (Gibbs et al., 2007).

Dependability refers to “consistency and care in the application of research practices ...” (Davies & Dodd, 2002, p. 280). Strategies that included identifying sexuality in terms of personal sexuality identity, family-social roles as men or women, and intimate/personal relationships assisted in promoting views of sexuality in a consistent framework and as less of a taboo topic. Audiotapes and verbatim transcriptions were completed in a timely manner to ensure that dependable data were collected. Multiple reviews were completed to assist in accurate portrayal of individual accounts (Ayers, 2007). A nursing faculty/research advisor was consulted to identify areas of overlap, ambiguity and vagueness of codes. Additionally, two African American (male and female) nurses who were also completing doctoral studies reviewed and coded separate transcripts. All of these nurses have experience with qualitative research that involves African American participants. Both have extensive health care and research experience that focus on concepts of femininity and masculinity – both of which are major aspects of sexuality.

All nurse consultants identified similar overarching themes of African Americans’ perceptions of sexuality since being on dialysis. In addition, the advisor provided feedback on the consistency of the emerging themes.

Confirmability refers to the objectivity of interpretations by the researcher (Guba & Lincoln, 1985). Multiple reviews of the data were completed to confirm the relationship between responses and categories for the present study (Ayers, 2007). A review of the data included discussions and code checks of the data with three nurse consultants. Additionally, a post interview summary and a reflective journal indicating how the data were coded and categorized assisted in establishing rigor for this research study.

Participants and sample selection. The population for this study was adult male and female African American individuals receiving hemodialysis. To be included in the population, these participants had to be at least 21 years of age, receiving out-patient hemodialysis for a minimum of three months, and assessed as functionally independent and cognitively intact.

A purposive sample of 20 participants or a sample that reached a level of data saturation that suggested informational redundancy was identified for recruitment (Sandelowski, 1995). Criteria for inclusion in the study required that participants be (a) self-identified as African American men and women, (b) able to speak, read, and write English, (c) between the ages of 21 and 60, (d) diagnosed with end-stage renal disease (ESRD) as adults, (e) receiving hemodialysis therapy for 3 or more months, (f) cognitively intact, and (g) not depressed. Participants were selected primarily from two Metro Detroit ambulatory dialysis centers associated with Wayne State University. Each dialysis center provides care for over 100 patients, with each patient dialyzed three times per week. African Americans comprised approximately 80 to 90% of the population in each center. Participants who have received at least three months of hemodialysis are presumed to have established a pattern associated with the dialysis regimen and have a greater awareness of this regimen's effect on perceived sexuality.

The age of 21 years was chosen because this is the legal age at which U. S. residents are able to participate in all adult activities. In addition, adults ranging from the age of 21 to 60 years are likely to be involved in or maintain sexual activity according to normative standards for most Americans. Sexuality is acknowledged to be an important aspect of health and general well-being for adults over the age of 60 years. However, higher incidences of sexuality concerns are suggested to exist in older adults due to changes in male and female sexual physiology, a lack of available partners, as well as health problems and effects of medications (Nusbaum, Singh, & Pyles, 2004). Diabetes, hypertension, and medications, such as beta blockers, are commonly

associated with both ESRD and physical sexual changes (e.g., erectile dysfunction; Doruk et. al., 2005; Palmer, 2003). Little is known, however, about what prompts individual discussions of sexuality concerns or an individual's request for interventions to enhance their sexuality. Therefore, patients were not excluded based solely on a primary diagnosis of either diabetes or hypertension or if they were using certain medications (e.g., beta blockers).

Manifestations of cognitive impairment occur more often in older individuals with ESRD than for other older adults (Kurella, Chertow, Luan, & Yaffe, 2004). Cognitive impairment can affect an individual's ability to provide informed consent (Hain, 2008). In addition, moderate or severe depression sometimes experienced by hemodialysis patients is suggested to be related to cognitive impairment (Rosenblatt, 2005).

Maximum variation sampling was used in this qualitative descriptive study. This sampling strategy allowed exploration of common and unique expressions related to sexuality across a broad range of demographically varied cases (Sandelowski, 1995). Some of the variations included experiences associated with the hemodialysis regimen (e.g., number of months/years on dialysis, emotions associated with dialysis, etc.) and demographic factors (e.g., age and gender).

Protection of human subjects. Prior to beginning this study, approval was obtained from the Wayne State University Human Investigation Committee (HIC) [see Appendix A]. Approval was obtained for continuation of the study beyond the initial deadline (see Appendix B). A letter of support and recruitment assistance for the study also was obtained from the Nephrology Department associated with the Wayne State School of Medicine (see Appendix C).

Sexuality research is a sensitive area of inquiry that intrudes into one's personal or private life (Lee, 1993). To support the study's recruitment and data collection strategies, sexuality was defined as being inclusive of appearance, feelings, desires, and expressions of

one's physical sexuality, personal sexuality identity, family-social roles as men or women, and intimate/personal relationships. This definition was proposed to minimize embarrassment or stigma that may have been associated with participation in this study. Potential risks to participants in this study were considered to be minimal.

Recruitment procedures. Issues of privacy and the ability to identify participants who met the inclusion criteria were a challenge to the recruitment of participants from two urban dialysis centers. Following approval by the HIC and to provide a solution to this potential barrier, the medical director for the participating centers distributed recruitment packages to potential research participants. A letter stating the purpose of the study, inclusion/exclusion criteria, role as a participant, identification of the principal investigator (PI) as an African American nurse practitioner with many years of clinical interviewing experience, and a contact number was included in each recruitment package (see Appendix D). In addition, a picture of the PI was placed on the recruitment letter to aid in providing appropriate personal identification to potential participants.

A section of the recruitment letter requested potential participants of the study to indicate their name and contact number, thus giving the PI permission to contact them. A postage-paid, preaddressed envelope was included in the recruitment package to encourage potential participants to return their expressions of interest in this study directly to the PI. Potential participants were also informed that a small gift of \$30.00 would be provided to show appreciation for the time that participants devoted to the study.

Additional methods of recruitment included asking participants to identify or inform other potential eligible participants of the study (snowballing). Nephrology nurses also were informed of this project during local American Nephrology Nurses Association (ANNA) meetings and were asked to identify other potential participants.

Data collection instruments. The data collection instruments specific to this qualitative study included the: MacNeill-Lichtenberg Decision Tree (Lichtenberg & MacNeill, 1999; MacNeill & Lichtenberg, 2000); Demographic, Medical History, and Sexuality Relationship Questionnaire; and the Sexuality Interview Guide. Appendix E, F, and G provides a copy of each of the instruments included in the study.

MacNeill-Lichtenberg Decision Tree (MLDT). The MLDT was used in this study as a screening tool to evaluate cognitive function and to rule out depression (Lichtenberg & MacNeill, 1999; MacNeill & Lichtenberg, 2000 [see Appendix E]). Scores on the MLDT are minimally correlated with age and education, and place low reliance on motor and language abilities. The Benton Temporal Orientation Test (BTOT) Benton, Hamsher, Varney, & Spreen, 1983) and the animal naming test (Crossley, D'Arcy, & Rawson, 1997) are included in the cognitive component of the MDLT. The BTOT assesses orientation to date, day of the week, and time. Scores greater than three error points have been cited as indicating moderate cognitive impairment for medical patients and were used as the cut points for this study (Benton et al.). The animal naming test is a verbal fluency task that requires naming as many animals as possible in a one minute time frame. Cognitive impairment is indicated in individuals who are unable to name at least 10 animals.

Psychosocial indicators and a three-item version of the Geriatric Depression Scale are included on the affective component of the MLDT (Brink, Yesavage, Lum, Heersema, Addley, & Rose, 1982). This section is only completed if the participant has more than three orientation errors or less than 10 animals named on the cognitive aspect of the MLDT. The psychosocial assessment provided an evaluation of whether participants lived alone, were able to make independent decisions for activities of daily living, and had family support if cognitively impaired. The three items on the Geriatric Depression Scale (GDS-3) have an adequate internal

consistency ($\alpha = .64$) and the highest correlation with the overall total GDS score (Parmalee, Katz, & Lawton, 1989; Rapp, Parisi, & Walsh, 1988). The MLDT took less than 5 minutes for each participant to complete.

According to Lichtenberg and MacNeill (1999), the three items assessing depression has excellent internal consistency. The sensitivity of the MLDT was .90, with a specificity of .81. The positive predictive power of .93 and negative predictive power of .74 provide evidence that the MLDT can be used to screen potential participants for cognition and depression.

Demographic, Medical History and Sexuality Relationship Questionnaire. The demographic, medical history, and sexuality relationship data for this study was obtained by using an original pen and paper self-report questionnaire developed by the researcher (see Appendix F). Items on this instrument included information pertaining to age, birth date, gender, marital, relationship status, educational level, and employment status. Additional survey items included age at first time of dialysis therapy, length of time on dialysis therapy, type of current and previous dialysis treatment, current diagnosis or treatment of medical problems, medications, and current or recent sexual activity history.

Sexuality Interview Guide. The PI developed a sexuality interview guide to obtain rich data from participants (Patton, 2002 [see Appendix G]). Content from the literature review, concepts from RAM (Roy, 2009; Roy & Anderson, 1999) and the SAM were used as guides in developing the open-ended questions and probes included in this guide. The Sexuality Interview Guide was used to elicit African Americans' perceptions of effects of the hemodialysis regimen on: a) physical body changes, b) personal sexuality identity and body image, c) family-social roles as men or women, and d) intimate/personal relationships. The investigator also elicited data pertaining to the influence of historical and sociocultural factors on African Americans'

perceptions of physical sexuality, personal sexuality identity, family-social roles as men or women, and intimate/personal relationships since being on dialysis.

Initial questions focused on less sensitive topics related to sexuality (e.g., descriptions of traditional male and female roles). These initial questions were asked to normalize concerns and minimize discomfort (Nusbaum, Hamilton, & Lenahan, 2003). Nusbaum et al. also maintained that participants' spontaneous reporting of sexual concerns is infrequent unless prompted. For these reasons, questions and probes were direct enough to allow participants to augment their responses and clarify issues related to sexuality. The open-ended questions focused on perceptions of individual sexuality in response to focal, contextual, and residual stimuli associated with their hemodialysis regimen. The probes were used to clarify and elicit perceptions of sexuality since beginning dialysis.

Pilot recruitment, data collection, and interview process. Prior to initiating the present study, a pilot recruitment, data collection, and interview process was completed (January to April 2007). This pilot work was initiated to determine the effectiveness of the recruitment process, refine interview questions and assess the investigators' interview skills. Refinement of content themes was not an objective of the pilot process. The pilot process was guided by a professor from Wayne State University College of Nursing who has expertise in qualitative methodology. After the pilot process confirmed the effectiveness of the recruitment process, four participants responded to recruitment letters that were distributed by a physician/medical director of nephrology at a Metro-Detroit dialysis center and engaged in pilot interviews that were audio taped. These audiotapes were transcribed into written transcripts with a review and feedback for each of the written transcripts provided by the professor. This process assisted in the development of the Sexuality Interview Guide and its subsequent revisions (presented in the section described as *Sexuality Interview Process and Alterations*).

Data collection procedures for study. Following receipt of the recruitment letter, potential participants made an initial phone or mail contact to the PI. Discussion of details of the study, assessment of basic eligibility (i.e., participant's ability to speak and understand English), and scheduling of a mutually agreed upon interview time and setting was made during the initial phone contact. Upon meeting with potential participants, the PI used a professional, but conversational format to increase participant comfort (Patton, 2002).

Participants were informed that participation in the study was voluntary and that they could elect not to answer questions with which they were uncomfortable. Participants were reassured that all information collected during the course of this study would be kept confidential to the extent permitted by law. They were informed that they could choose to withdraw from the study at any time without prejudice. Each participant was given a copy of the informed consent that was read aloud by the PI. This strategy assisted in providing clear statements of all study information and minimized any embarrassment related to possible individual literacy problems. Each participant was also given an opportunity to ask questions before signing the consent form. Consent to participate was obtained from all participants (see Appendix H). None of the participants withdrew after consenting to participate in the study nor did they express discomfort with the study.

The initial screening process allowed the PI to redetermine each participant's eligibility for the study. This process included observation of each participant's physical and mental state at the beginning of the interview. The screening process also included the completion of the MDLT cognitive function test. No indications of either cognitive impairment or clinical diagnosis of depression were noted for any of the participants screened for inclusion in the study. Following consent and initial screening, each participant was asked to answer questions from the

Demographic, Medical History and Sexuality Relationship Questionnaire. To ensure clarity, these questions were read aloud and recorded on the questionnaire by the PI.

The PI conducted all interviews. Each interview was audio-taped. An alpha code was used to identify participants and their data. The audiotapes were used to support or clarify information obtained by the researcher. Names that were inadvertently mentioned on the audiotapes were omitted during data transcription. Investigator notes, tapes, transcripts, and a codebook linking the tapes and transcripts to participants were kept in separate locked files in the researcher's home office.

A digital recorder was used to minimize functional problems and loss of information before beginning the sexuality interview. The PI also made occasional paper and pencil notes during and after each interview. This process assisted with highlighting specific areas of participants' concerns or of the PI's perceptions of strong or limited responses.

Sexuality interview process and alterations. Initially, the first question of the sexuality interview guide was open ended and asked participants to describe individual perceptions of their sexuality since being on hemodialysis. However, this question was found to be too vague. After the 2nd interview, the PI recognized that the initial question needed to be more focused on holistic perspectives of sexuality or on what being a man or woman meant to the participant. Following the introduction, the initial question was changed to: "often, when seeing a particular man or woman, one hears the phrase – He/She is all man/woman, describe in your opinion that man/woman?" For each question, a set of probes were used to focus on coping responses and behaviors related to each of the four adaptive modes. The probes included questions related to: 1) self-identity and body image (personal sexuality modes), 2) family-social roles as men or women (family-social role mode), 3) intimate relationships (intimate/personal sexuality mode), and 4) physical changes and physical sexual functioning (physical sexuality mode). This question aided

in constructing a picture of each individual's views of being a man or woman. The question also helped identify holistic aspects of participants' sexuality.

The first question was followed by: How would you describe yourself as a man/woman? This question helped each individual to focus on their personal sexuality identity. The question also provided a foundation to assess changes in participants' perceptions of sexuality since being on dialysis (see Appendix K; actual sample interview).

Specific questions were then asked about effects of hemodialysis on each individual's personal sexuality identity and body image, family-social roles men or women, physical body, and intimate relationships: "Describe how hemodialysis and the routine associated with dialysis has affected you as a man/woman?"

Later questions extended the focus on perceptions of sexuality since being on dialysis by asking participants to compare themselves to other men/women who were on and not on dialysis: a) "how would you compare yourself to other men/women who are on dialysis?" and b) "How would you compare yourself to other men/women who are not on dialysis?"

An additional question was asked to determine the effect of non-obvious racial perspectives (residual stimuli): "Do you think that any of the concerns that you have mentioned would be different if you were not African American?" The last question was open-ended and allowed the participant to elaborate on any other concerns related to dialysis and its effects on their sexuality: "What else would you like health professionals to understand about the dialysis routine and how it affects your identity, relationships, and family-social roles as a man/woman?"

The interview guide and revisions were reviewed for accurate reflections (content validity) of the phenomenon of sexuality and dialysis by a nurse practitioner and nephrologist who had extensive experience in the care of patients receiving hemodialysis treatment. Content

also was reviewed by a clinical nurse specialist who had clinical and research experience in human sexuality.

A post interview summary form (see Appendix I) was used to supplement the PI's notes taken during the sexuality interview. This form was used to summarize main concepts/themes from each interview, identify questions that provoked strong responses from participants, and identify new questions that were stimulated by the interviews. This form was used to record anecdotal comments regarding the interview that was not apparent on the audiotape (e.g., body language, facial expressions, etc.).

Data collection sessions ranged from 21 minutes to one hour and 48 minutes. The average time was 35 minutes. The PI also asked each participant for permission to make a phone or personal follow-up visit to illuminate any answers requiring clarification. Despite being granted permission by all participants, attempts for further post-interview phone follow-up to clarify or expand initial responses were often unsuccessful. Either the phone numbers were unlisted or participants did not respond to phone messages (a minimal of three phone messages were left in two cases and one phone number was unlisted).

Recruitment and interview timeline. The recruitment and interview period lasted 11 months - from September, 2008 to May 2009. Nineteen participants were interviewed following the initial contact to reschedule appointments; three additional participants cancelled their scheduled interviews. A final attempt to reschedule interviews with each participant was unsuccessful.

Although data saturation had been reached, an additional three months of active recruitment was conducted after the 19th interview to obtain a minimum initial goal of 20 participants. This effort was unsuccessful, and at the end of this period, analysis of data was completed for all participants.

Data Management/Analysis

Data analysis occurred concurrently with data collection. Audio files from the digital recordings were reviewed to ensure clarity and completeness of each interview. Each interview was transcribed into a computer file and printed to provide a paper record. The paper copy was compared with the audiotape for accuracy. Analytic memos from notes taken during the interview and the post interview summary guide were reviewed in combination with the transcripts. Verbal and nonverbal notes from the analytic memos were placed in chronological order and inserted, as notes into the transcripts.

NVivo 8. NVivo 8 qualitative software was used for the majority of the data analysis. The content of each transcript was imported into NVivo to isolate and code themes related to the research questions and specific aim (Barry, 1998). This program also assisted in later retrieval of data for continued analysis.

Initially, data were reviewed line by line within each paragraph of individual interviews. Data were coded and listed according to the topical areas suggested by the theoretical framework and research questions (e.g., perception of physical sexuality; Strauss & Corbin, 1990). Additional categories were added to identify themes that did not fit under the topical areas or broad categories (e.g., perceptions of roles of hemodialysis staff). Criteria that provided the rationale for each category or subcategory were identified (e.g., identification of the theoretical framework influencing men's perceptions of physical sexuality). Based on the identified criteria, some categories were merged. Data saturation was identified by the replication of data within categories (Gibbs et al., 2007). In the final stage of analysis, codes were evaluated for fit under categories for each adaptive mode. Any data that did not fit into one of these categories were categorized under alternative concepts.

Demographic analysis. PASW-SPSS for Windows, ver. 17 was used to conduct simple descriptive statistical analysis of the demographic data. The demographic data also were entered as codes into the NVivo software (e.g., age, gender, etc.) to determine linkages between themes and participant's demographics.

CHAPTER FOUR

RESULTS

The goal of this qualitative study was to describe and facilitate understanding of African Americans' perceptions of sexuality since being on hemodialysis. Characteristics of sexuality for the purpose of this study included physical sexuality, personal sexuality identity, family-social roles as men or women, and intimate/personal relationships.. This chapter describes the sample and presents primary findings/themes identified from the interview data.

Description of Sample

Nineteen participants met the inclusion criteria and consented to participate in the study. Eighteen participants received hemodialysis treatments in two urban ambulatory dialysis centers, with one participant in home hemodialysis treatment three days/week for a minimum of three hours each session. All interviews were conducted by the primary investigator (PI). Fourteen interviews were conducted in participants' homes and the remaining five were conducted in other prearranged, convenient private settings (i.e., a local university campus library, a community health clinic, and the PI's office located in a local university building). None of the participants reported personal emotional distress related to the interview questions and/or specific interview settings.

The final sample consisted of 12 men and 7 women (see Table 1). This ratio of men to women is representative of the usual ratio of men to women on hemodialysis (United States Renal Data Source [USRDS], 2009). Participants' ages ranged from 37 to 59 years ($M = 49.95$, $SD = 6.87$). Seven participants (3 males and 4 females) were under 50 years of age with 1 participant under the age of 40 years.

Table 1

Participants Socioeconomic Demographics

Male Participants	Age	Education	Employment
B	50	Some college	No
C	50	Some college	No
D	50	Some college	No
F	56	Less high school	Retired
H	59	Less high school	No
L	42	College degree	Yes
M	54	Some college	No
N	56	College degree	Part-time
O	55	Less high school	No
P	58	High school	No
Q	43	College degree	Part-time and graduate student
S	42	Some college	No
Female Participants			
A	55	College degree	Yes
E	37	Some college	No
G	53	Less high school	No
I	58	High school	Retired
J	41	High school	No
K	42	Some college	No
R	48	Some college	No

Note. Participants are listed alphabetically according to order of interviews.

The educational background of the participants ranged from less than high school to college, with 4 participants reporting a college degree. The majority of the participants were unemployed (n = 13; see Table 1), which is common among the dialysis population (Markell, et al., 1997).

Table 2

Participants Relationship Demographics

Male Participants	Age	Marital Status	Sexually Active	Date Last Sexual Active
B	50	Single/Relationship	Yes	2 months
C	50	Divorced	No	1.5 years
D	50	Divorced	No	3.5 years
F	56	Married	Yes	2 months
H	59	Divorced	No	1 month
L	42	Single	No	8 years
M	54	Single/Relationship	Yes	1 month
N	56	Married	Yes	2 days
O	55	Live-in- Relationship	No	2 years
P	58	Separated/Relationship	Yes	1 week
Q	43	Single	Yes	1 night
S	42	Married	Yes	4 days
Female Participants				
A	55	Divorced	No	19 years
E	37	Divorced	No	4 months
G	53	Divorced	No	2 years
I	58	Single	No	7 years
J	41	Single	No	4 years
K	42	Divorced	No	2 years
R	48	Married	Yes	1 month

Note. Participants are listed alphabetically according to order of interviews.

Seven male participants were either married, had a live-in-partner, or were in a steady relationship. Sexual activity at the time of the interview was reported by six of these males with last date of sexual activity ranging from 2 days to 2 months of their interview dates. The seventh male reported no sexual activity and not being sexually active for two years. Three remaining males were divorced and the two were single. None of the divorced or single males reported a steady relationship. However, one male reported sexual activity the night before his interview.

In comparison to the males, 1 of the 7 female participants reported she was married and sexually active one month prior to her interview. The remaining female participants reported their marital status as either divorced (n = 4) or single (n = 2). None of these six participants reported being in a steady relationship.

Table 3.

Participants Hemodialysis History

Male Participants	Age	Years on Dialysis	Dialysis Associated Medical History*
B	50	5.00	DM/HTN
C	50	1.00	DM/HTN
D	50	4.00	DM/HTN
F	56	9.00	HTN
H	59	1.00	DM/HTN
L	42	7.00	Polycystic Kidney
M	54	2.11	HTN
N	56	4.50	HTN
O	55	4.00	DM/HTN
P	58	1.50	HTN
Q	43	4.00	HTN
S	42	9.00	HTN
Female Participants			
A	55	5.00	Polycystic Kidney
E	37	3.50	DM/HTN
G	53	2.00	HTN
I	58	1.00	DM/HTN
J	41	7.50	HTN
K	42	1.30	DM/HTN
R	48	10.00	DM/HTN

Note. Participants are listed alphabetically according to order of interviews

*DM = Diabetes Mellitus

HTN = Hypertension

The range of years for all participants receiving hemodialysis treatment was from 1 to 10 years (M = 4.16, SD = 3.08). There were no statistically significant differences in range of years

for receiving hemodialysis treatment between the male and female participants, $t(17) = .01$, $p = .992$. Hypertension and hypertension in combination with diabetes were reported as primary medical diagnoses associated with end stage renal disease (ESRD) for most participants ($n = 17$). Two participants (1 male and 1 female) indicated polycystic kidney disease as primary diagnosis for kidney failure.

Findings from Interview Data

Four themes were identified as primary contributors to participants' perceptions of sexuality. The first theme was identified from the participants' beliefs about gender roles and the influence on perceptions of sexuality: endorsement of gender ideology influences perceptions of sexuality. The second theme emerged from participants' concerns regarding physical sexuality: diminished physical sexuality represents more than the physical sex act. The third theme emerged from participants' perceptions and responses to hemodialysis associated stressors: the hemodialysis regimen is an emotional rollercoaster. The fourth theme, only people experiencing dialysis understand, was identified by participants' perceptions of mutual support systems within dialysis centers. Participants' passionate responses follow each theme.

Theme 1: Endorsement of gender ideology influences perceptions of sexuality. To assist participants with identifying sexuality from a holistic viewpoint, each was asked to describe in his or her opinion, characteristics of being "all man or woman." This theme emerged from male and female participants' descriptions which suggested a difference in cultural beliefs about gender roles and their influence on perceptions of sexuality. The 12 male participants' descriptions of "all man" included behaviors that were considered to be traditional male roles and suggested an endorsement of traditional masculinity ideology (e.g., provider for family). This endorsement was persistently reflected in the male participants' descriptions of their sexuality.

In comparison, female participants predominantly identified “all woman” as “mother/caregiver.” Additionally, participants who were single mothers primarily expressed concern about altered personal roles as mothers. These views suggested an endorsement of traditional femininity ideology. Traditional femininity ideology is associated with an image of a woman who primarily focuses her attention and care on others. While, the female participants in this study were found to endorse aspects of traditional femininity ideology (detailed later in the paper), their level of endorsement was not as fixed as the level of traditional masculinity endorsement by male participants.

Male participants described male roles that included: (a) being a supporter, (b) dependable, (c) having physical strength and abilities, and (d) being able to deal with adversity. All descriptions were similar in that each participant indicated a need to preserve an image of being able to handle anything. Male participants defined the “all man” image as a supporter, strong, and dependable (n = 8). A more limited, but still passionate view of the “all man” image was identified as a man who is able to deal with adversity (n = 1). Physical appearance was not indicated as a relevant aspect of being all man by any of the participants. Participants’ descriptions of prescribed male roles demonstrated coping and adaptive strategies to maintain a “manly” sense of control and confidence. All male participants’ responses suggested that limitations of traditional male roles represent a diminished image of being “all man. The implications of perceived negative images of physical sexuality identity, personal sexuality identity, family-social roles, and intimate/personal relationships are suggested to be of concern to men who experience chronic illnesses and treatments.

The descriptions of supporter projected images of men who care about others. Male participants’ supportive behaviors focused on care of family. The implication of being able to care for family and others is suggested to be a demonstration of maintaining the all man image

despite limitations of ESRD and hemodialysis regimens. This all man image is suggested to promote a strong sense of “who I am as a man” and to promote other effective coping and adaptive processes.

Personal demographics of eight male participants (C, F, H, L, N, O, P, and S) who presented views of “all man” as supporter, strong and dependable were varied. Their ages ranged from 42 years to 59 years. Marital statuses varied from single, married or in stable relationships, and being divorced (see Table 2). Two participants were college graduates and reported part-time employment (see Table 1). The remaining participants were unemployed at the time of the study. Expressed views of the all man image from all male participants were similar as indicated by the following examples:

Me, I always thought being a supporter, being a head of something. Men are strong, being able to maintain. (Participant C).

A strong guy that takes care of his family, can be depended upon, good in the community, helpful to his neighbors and to his other family members (Participant F).

It’s more the provider, the person who is in charge and in control of the situation. . . . the man being the bread winner and the man being the take charge, in control, head of the household type. (Participant L).

A man who takes care of his family and obligations. . . . a man who is . . . understanding and devoted to his partner, his wife and loves his family. To me, that’s all man. (Participant N).

A man that’s strong, that’s able to . . . do physical things about the home, and someone who’ll protect and be a valuable person towards his family. (Participant S).

Descriptions of “all man” as one who is able to “deal with adversity” were expressed by a younger participant. This participant was single and reported having no children. He was a graduate student who expressed pride in his continued studies and part-time employment role despite the impact of the dialysis regimen on his time; and potential for alterations in his personal sexuality identity or perceived responsibilities as a man:

As far as being a man, I think it's your dealing with adversity, what makes you the kind of person you're are going to be. (Participant Q).

Male participants often reported pride in their abilities to live “normally” and carry out prescribed male roles (e.g., provider) despite actual or potential effects of the hemodialysis regimen on sexuality. Older male participants (B, F, M, N, and P) who reported being involved in a current relationship particularly reported pride in looking like and being a “normal man.” The length of dialysis years varied widely for these participants. The continuation of prescribed male roles as a supporter and being dependable was noted as a recurring element of participants' perceptions of what it was to be normal. Pride in assuming responsibilities for family roles was discussed by two older male participants:

Just because I'm on dialysis, that don't mean that my wife, my daughter, my son, my grandbabies don't still – my dogs – don't still depend on me. . . . days, I go to dialysis, it's just like days that I don't cause when I leave dialysis, I be off and running. Oh yeah, they (others not on dialysis) don't have nothing on me. I can do the same thing they do. Anything they do, I can do. (Participant F).

I take care of my family. You know, I do what I'm supposed to do as a man to, you know, contribute to what I'm supposed to contribute . . . I feel like I'm a man. I feel like I got respect, the position that I'm in and I try to carry myself in a way that people can respect me. Sex is not all of it. It's really your personality and your character, and I feel like I conduct myself as that . . . me and my wife [currently separated] still have a relationship because we're doing it because of the family and my children and we still have a good relationship. (Participant P).

Not acting sick or allowing one's personal sexuality identity to be defined by an illness also was suggested by a younger and older male participant to increase perceptions of normality:

People always say, You don't look like you're on dialysis. You don't act like you're on dialysis. I mean, because I don't really – you know, it's not a defining thing for me. It's just a part of what I am. I don't deny that, but I don't let it just define my existence. (Participant L).

She [neighbor] said, you don't look like you sick. Every time I look up, you going up and down the street, you going around . . . I said, I'm not going to let this get me . . . , I'm not letting this get me down. (Participant M).

A focus on the continuation of normative patterns of daily activities is suggested as an adaptive means of minimizing (or prohibiting) an altered sense of “who I am as a man”. The two previously mentioned participants along with four other male participants (D, F, P, and Q) elaborated on their active roles with their family, church, and community. Ages, relationship status, and the number of year on dialysis varied widely for these male participants (see Table 2, 3). Two participants emphasized that their personal lives were directed only by Christian principles as a reason for not allowing dialysis to define them.

God saw fit to allow me to go on . . . gonna walk with Christ. I promised God, that I would never ever walk away from Him again and so from that point, I was, you know going to church and this and another; and becoming more and more involved... (Participant D).

Life is in God’s hands and I feel like God has made a way through the machine to be a asset to this type of treatment ... You know, because it’s not all over if you got the faith and believe in God. I’m a firm believer that God made the body, that He can do it [keep you alive]. (Participant P).

Participant F and Q’s responses also supported the assumption that the dialysis regimen was not going to take precedence over other roles/activities in life. Accepting the challenges of dialysis as a small aspect of life in comparison to other primary roles (e.g., provider for family, etc.) is suggested to be an adaptive process that minimizes or prevents the loss of “who I am as a man.”

I don’t know if it’s mental, I won’t accept letting hemodialysis keep me down. That’s just another part of life that I’m going through . . . (Participant F).

If anything dialysis has taught me that, uh, disease will not define you. You’re defined by what you do. . . . The best way that I can answer your question as to what kind of person I am or what kind of man I am. I don’t think dialysis will define you if you have a life. (Participant Q).

One female (R) focused on not allowing dialysis to define her. Participant R acknowledged that she was aware of the negative effects of hemodialysis. However, she indicated that dialysis did not “make her world stop” or interfere with roles as a wife and mother.

The suggestion by this participant was that having a strong mental acceptance of what a person is able to do versus dwelling on the negatives of dialysis was key to continuing to be “all woman.”

I say that sounds like me, like she’s all woman. . . . not letting the dialysis interfere with what I need to do or what I want to do. . . . that sound like me, all woman. I don’t know, just being a wife, a mom, doing stuff with the kids. Yeah, that’s me.

I walk there and I walk back and, um, most people who be [sic] on dialysis, after they finish, they go home and rest for the rest of the day, and I’ve never been tired. All my 10 years on dialysis, I’ve never been tired. . . . I’ll say the Lord always put me in the position where I can walk to dialysis and walk home. When I get off the machine, I walk home, check to see what my husband –if he wants to do anything. If not, I’m gone. I got my little disability bus card, pay 50 cent and a dime for a transfer. I go anywhere I want to go. I take it as a spiritual thing. . . . I’m what’s happening. Most women at this dialysis are older and act older. They act like they so old. I don’t – Baby, I come in there like a spring chicken every . . . even if you are older, you don’t have to, uh, act that way. I try to tell them it’s a mind thing, y’all. It’s all in your mind. You can do whatever you want to do if you put your mind to it. (Participant R).

Though, this female participant expressed a focus on her family, her responses did not suggest an over endorsement of traditional feminine ideology, but pride in her perceptions of herself as resourceful and independent. Descriptions of a strong family support system and strong faith were identified as contributing factors to this participant’s sense of being “all woman.”

In comparison to the above male and female responses, three male participants (H, M, and P) asserted that it is a man’s role to accept the hand you are dealt. Responses of these older male participants suggested an endorsement of traditional masculinity. Each of these participants reported that they lived alone and had been on dialysis for fewer years (1 year, 2.11 years, and 1.5 years respectively) than other male participants. These responses suggested the employment of coping strategies to minimize dissatisfaction with their sexuality by playing the hand they were dealt:

I’m not gonna say it [dialysis] has affected me as a man. I just feel that you have to play the hand you’re dealt. (Participant H).

I just got to handle what I got to handle . . . He (God) didn't put me out. He put me on a machine, okay. I'm glad to be here. If that's what gonna keep me here, let's do this, you know. . . (Participant M).

That's going to be part of my life and I have to learn to accept it. So right now, I accept it. (Participant P).

A focus on feminine appearance has been suggested to support an endorsement of traditional femininity ideology for African American women (Cole & Zucker, 2007). This endorsement was also implied in this study by female participants' negative responses regarding hemodialysis surgical scars. However, the perceptions of dialysis-associated scars for these women suggested an erosion of "who I am as women" that exceeded general concepts of physical beauty. Younger female participants (E, J, K, and R) expressed greater concern regarding the appearance of hemodialysis associated scars than the older female participants. Descriptions of their surgical scars and other peoples' responses to them were elaborated by the following participants:

I hate the disfigurement that it has bought to my arms, ah, the scars are atrocious and ugly. My colleagues staring at them and wincing at my scars and my arms used to be perfect, skin-wise. I mean no scars, smooth skin, no discolorations. I feel cheated, because for the rest of my life there is not a thing I can do about it. (Participant A).

The scars that I get from the surgeries, they ugly. And I like to wear like to wear like low-cut tops. I used to like to wear halter tops and, you know, different little things, nice little skirts. Hmmm, not really, not anymore. Because I got little scars . . . (Participant E).
Oh, horribly, horribly, because I hate to wear short sleeves. You see all these scars on my arms. Oh, yes. I . . . sometimes I try to cover it up . . . (Participant R).

Women's perceptions of each other's hemodialysis associated scars are suggested to add further personal distress. However, Participant J suggested that personal scars were not a topic of discussion among women in the dialysis centers. This response implies that hemodialysis associated scars represent deeper erosions into one's sense of "who I am as a woman" that are not be as easily shared with others.

We [women at dialysis center] have a lot of conversation. I have never really ever talked about the scars. I don't think any of us have ever just really talked about our scars. (Participant J).

In contrast to the female participants, male participants indicated that hemodialysis scars were not associated with loss of who they were as men. Seven male participants (F, L, M, N, O, P, and S) ranging from 42 to 59 years elaborated on this subject. The years on dialysis for these participants (which are suggested to influence the amount and appearance of associated dialysis scars) varied from 1.5 to 9 years. Two participants suggested that hemodialysis associated scars are simply viewed as a part of what you have to go through to maintain life than as an aspect of altered body image. This view was reflected in the following participants' response:

The body scaring, it's, I don't like it, but, I mean you got to live with it because of the situation. (Participant S).

The remaining five male participants described their scars as "not bad" in comparison to the scars of others. This comparative process again suggests that most men do not associate their scars with an alteration of who they are as men. These views of the male participants further suggested an endorsement of traditional masculinity which supports the image of men being able to handle anything. Participant F's response best captures this view:

I don't think mine [scars] is real bad ... some guys ... knots are real bad. ... it's ugly, but I don't hide mine. I'm not ashamed of them and I don't consider them as bad considering other peoples. (Participant F).

Altered family-social roles and gender ideology endorsement. Both male and female participants expressed concern about altered family-social roles since being on hemodialysis. The alteration in roles for the men focused on changes in social and work lives. In comparison, the women focused on alterations in their roles as a mother. Five male participants particularly described *being stuck*, *change in life as a normal man*, and *missing out*. Two participants (C and H) were single, not involved in committed relationships, and had little contact with other family and friends. Participant C expressed negative emotions associated with his isolation from social

support systems and self support as a man (living in elderly parent's home for past 6 months) since being on hemodialysis. This isolation effect is thought to play a primary role in altering this individual's perception of his personal sexuality identity and family-social roles as a man.

I can't do the things that I want to do. I can't make the money I would like to make. I can't really do what I want to do, I'm stuck. . . . I had friends, I can't do things no more, I can't go nowhere. Then when my friends, especially want to travel, I love to travel. I can't travel no more. I got to go, if I want to leave and go out of state, I have to make an appointment two months ahead to be able to take dialysis out of state. But see my travel be the spur of the moment, we never plan trips. [When] my cousins or friends get together, I can't go, I got to stay around. Nobody comes around, I don't see nobody. You know, cause, I can't do it . . . And uh, I 'm dealing with that and then me staying home. I ain't been home since I was 18 years old, I'm 50, a 50 years old man living with my parents (exclaiming loudly), that's not a good feeling either. I'm missing out on my fun time. Their schedule can't fit my schedule and my schedule can't fit theirs and see that affects my life. I, I miss fishing and all I do is just go home. I go to dialysis and come home and sit here. . . . My whole life style, dialysis has changed my life completely, completely. . . . when I first got on dialysis, people still call, call, call, but I be telling them, I can't do it no more, I can't do it no more, and when they realize that I can't be there for them no more, my phone barely rings, barely rings.(Participant C).

The remaining three male participants (B, M, and S) reported involvement with family and friends. They also were involved in intimate relationships. However, these participants also indicated that time commitments and physical alterations associated with hemodialysis contributed to being unable to fully provide for, and support family, friends, and intimate relationships. The following responses suggested that despite caring family and friends, a sense of "who I am as a man" can be affected by perceptions of altered family-social roles and isolation:

Some of my closest friends and family – they just forget that I even have to go to dialysis, you know . . . I'm just saying in general, I'm missing out on certain things. Like the Holiday that just passed by, every Holiday this year fell on a Monday, or Wed or Friday, [voice lowers]. (Participant B).

Like I say, I'm a master plumber carpenter and usually I can do 10 or 12 hours at the job, you know. I'm talking about in a ditch digging, jack hammering, all that stuff. Now – well when I – I did it I think two months after I was on dialysis. I did it two months and I literally just grabbed the shovel and hung on. My nephews looked at me. They say, "Unc, you all right?" I say, "I ain't [sic] got it no more." You know, and that hurt me. That hurt me. (Participant M).

The days I do go to dialysis I just don't feel like I'm that particular person [all man] because I be drained. I can't get up and play with my son. He wants to play basketball, throw the ball around. I'm not able to do that because I be too tired, . . . You know, me and him go out there, cut the grass, . . . wash the car, the truck, you know, play baseball, throw the football around, . . . ride the bikes up and down the street when we can. But it's days he – Monday and Wednesday and Fridays he want to do it, I can't do it, and he be like, "Why?," but he really don't understand because he six. . . . I was never without a job. I always had a job, and when this happened to me and now everything is limited. I still feel funny not doing a lot of work I used to do, because I'm used to getting up at 5:00 in the morning and working all day – not just sitting around the house not doing nothing. (Participant S).

In comparison to male participants, female participants' responses regarding the effect of hemodialysis on personal sexuality were focused on alterations of their roles as mothers and providers for their children. The older female participant A suggested that the selfless role as mother was an important aspect of her personal sexual identity. This participant's descriptions were indicative of an endorsement of traditional femininity ideology:

It definitely affects my role as a mother, because I believe that it distracts from my ability to be a better mother. Ah, not, I mean for example, my children like for me to cook . . . They like for me to make them something and it makes them feel happy and it makes me feel happy when they are happy. (Participant A)

However, African American women who are heads of their families also have been labeled as "strong." Being strong is suggested to be reflective of more than the selfless caregiver, but also the breadwinner, primary disciplinarian and both matriarch and patriarch for this Black woman's family. Participants E and K's responses suggested that limitations of physical abilities, time, energy, finances, and persistent negative emotions associated with "dialysis days" strongly alter patients' personal sexuality identity, family-social role functions and intimate/personal relationships for this "strong" and now more vulnerable woman:

I used to work . . . I enjoy working and it's a big difference when you can't work to jumping to disability . . . I feel bad sometime when my daughters ask me for something and I tell them I have to wait 'til I done paid the bills or bought the groceries to see what's basically left over, and I'm not used to that and they're not used to that. . . . that makes me feel horrible. If they even come to me and ask me for a dollar and I don't have that dollar [silent pause] . . . I used to get out and be active with them [daughters]. We would go to the mall, even if we just had lunch and split it between the three of us, you

know, we would do that, and, you know, just walk around and look at things or, you know, go to the park or, you know. Now I can't really do that because I get tired quick. (Participant E).

It has changed me as a mother tremendously because I cannot take the stress. I'm more focused on, uh, dialysis days and non-dialysis days, and pretty much my youngest have gotten away with a whole lot that the older ones didn't get away with, . . . but I just don't have the energy, the persistence. I'm not consistent. I'm not persistent because I don't feel good so I'm just – it's like whatever. I'll deal with it later and then, you know, so as a mother, I have just – I'm not going to say given up, but I'm not consistent as I was two years ago, and it kind of – it shows . . . (Participant K).

Participant K (above) also reported symptoms of depression that commonly have been associated with dialysis and is suggested to heighten perceptions of altered sexuality:

Since dialysis, I take one day at a time. I'm not as – I'm not what I used to be because of my illness, it seems like if I just wake up, that's enough. [Before, I was] oh, energetic, uh, wouldn't mind doing something for the first time or just wouldn't mind going out into I say now society to where I'm more home bound now by choice. (Participant K).

The results of the MacNeill-Lichtenberg Decision Tree (Lichtenberg & MacNeil, 1999; MacNeil & Lichtenberg, 2000) screen used in this study did not indicate a clinical diagnosis of depression for any participants in this study. However, participant G, a divorced mother of older children, all of whom lived out of the home, also reported feeling depressed:

I stay depressed most of the time, you know. . . . cause I used to be all woman, what you call a all woman, but now I'm not. I don't consider myself that . . . I used to put a lot into myself, you know, about taking care of my hair, putting on makeup, dressing very well, and I still, when I go out, you know. I still keep up my appearance, you know, but I [before dialysis] Oh, I'd be gone. I'd be in the street somewhere. Going shopping downtown, walking around. I'd find me something to do . . . The week days about going to dialysis, you know, going, just going every other day. It seems like a treadmill, like I'm going every day when I don't really get no break in that one day in between, you know, cause I still be tired from the day before, you know. On the weekends the only time I get fresh, a breath cause I get two days off in a row . . . and then like I say, I feel refreshed. Now I got to go right back tomorrow. Like I say, back to the treadmill. (Participant G).

Participants G and K were the only participants of either gender group to report specific symptoms associated with depression. These women associated their feelings of depression to their diminished energy and time committed to dialysis. Both participants reported a change from

being outgoing to being either home bound or at dialysis. Additionally, both women attributed their perceptions of depression to a loss of being “all woman.” Despite an 11-year age gap, similar characteristics for these women included being: divorced, single parents, and on dialysis for a shorter number of years (2 and 1.3 years respectively). Participants’ (G and K) responses suggested that women in the earlier periods of dialysis are at greater risk for erosion of their personal sexuality identity or how they identify as women. These life-altering changes are suggested to be true of women who have additional, yet different responsibilities as parents. The minimization of personal sexual identity also has been found to influence family and social role interactions outside the home.

To expand the exploration of perceptions of sexuality since being on dialysis, participants were asked, “How would you compare yourself to others who are on dialysis?” The general response from all participants was that they did not define their sexuality in response to others either on or not on dialysis. However, women of varied ages were more likely to report envy/jealousy regarding loss of time and energy. These losses are suggested to contribute to a sense of altered personal sexuality identity and family-social roles as a woman (e.g., time away from role as mother) as demonstrated by the following examples:

Well, I am jealous of them [people who are not on dialysis], envious of the fact that they have all that extra time and that part of their life. (Participant A).

They have a different respect. They’re more energetic. They do get – some of them can get more things done, like I would if I wasn’t on dialysis, or that I didn’t have to deal with kidney failure at all. (Participant J).

They have a lot more going for, the people, women that are on dialysis. I mean that’s, uh, three, six, nine – that’s 15 hours [per week] of my life being on dialysis. (Participant K).

In comparison, the male participants’ responses regarding comparison to others on dialysis again suggested the influence of their endorsement of traditional masculinity ideology. Four male participants acknowledged the challenges of dialysis, but asserted that they were

better off than most men on dialysis. These participants included two of the younger men (L and S) and two of the older men (F and P). Relationship status and years on dialysis also varied. These participants' responses indicated a focus on the man's role to be "able to handle anything." The following participants' responses suggested the employment of coping processes and adaptive responses that were influenced by an endorsement of traditional masculinity ideology:

I know how I feel as a man on dialysis. It don't bother me and, and – maybe at my age cause you know I see a lot of younger guys on hemodialysis now, and maybe at my age I – maybe I'm a whole lot better off than most guys . . . (Participant F).

I would imagine I'd do as well or better than most because I'd probably do well or better than most dialysis patients, period (Participant L).

I feel like I'm doing good compared to some of them that I see in there that's complaining and they said they don't know, um, how it's gonna work for them. They be [sic] talking about things like they not going to live long. I feel like that I will because of my strong mind. (Participant P).

I think I'm one of the better men that I can see that's been on dialysis for a long time because most of the men that I do see that's on dialysis now, and they ain't even been on it longer than me, they look like they be just out of it all the time . . . I basically try to do everything I can. I'm not fixing to try to limit myself. (Participant S).

Theme 2: Diminished physical sexuality represents more than physical sex.

Responses from both male and female participants supported the assertion that hemodialysis therapy commonly leads to diminished physical sexuality. However, the degrees of diminished physical sexuality and individual responses to their diminished state differed for each participant.

Over 50% of male participants (B, F, M, N, P, Q, and S) described themselves as sexually active (see Table 2). Report of most recent date/day of sexual activity ranged from past night to two months. All but one of these men were either married or involved in a committed relationship. The age range of these participants was 42 to 58 years. The range of dialysis years was 1.5 to 9 years (see Table 3). No substantial difference was noted between years of dialysis and most recent date/day of sexual activity. All 12 male participants had been diagnosed with either hypertension or a combination of diabetes and hypertension; both of which have been

associated with erectile dysfunction. However, this association was not explored in the present study.

Ages for the five non-sexually active participants ranged from 42 to 55 years (see Table 2). The range of dialysis years for the non-sexually active participants was 1 to 7 years (see Table 3). Participant O reported being in a steady relationship and non-sexually active for two years. Participant L reported abstinence for the past eight years. In comparison to the men, participant R was the only female to report a committed relationship (married) and sexual activity one month prior to her interview. All other women reported dates of last sexual activity as 2 or more years.

Male participants with partners were particularly concerned about altered partner relationships. The importance of this concern was further expressed by a desire for health professionals' to be more involved in helping to repair altered relationships. Participants discussed barriers to communication and suggestions for facilitating discussions with health professionals.

Both single male and female participants suggested that the hemodialysis regimen was detrimental to establishing steady relationships. All responses indicated that diminished physical sexuality involved more than individuals' concern about their physical sexual ability.

The overarching theme relevant to physical sexuality and intimate relationships by study participants was diminished physical sexuality represents more than physical sex. Despite reports of being sexually active by a majority of male participants, six men (B, H, M, N, O, and S) reported diminished physical sexuality. These participants reported being married or involved in a committed relationship. Most of these participants' responses indicated a slow progression of their diminished physical sexuality state. Descriptions of thoughts and behaviors related to this altered state also suggested varying levels of coping and adaptive responses.

I don't feel that drive like I used to have. You know, I felt like I needed it every other, every day (laughs). But, now it doesn't you know. (Participant B).

I got a penile implant and that; I guess it kept my urge up for about the last, up until the last two, three years, 'cause I just don't get the urge no more. (Participant H).

Like for instance today, uh, I had dialysis, all right, and I know that I probably would not feel – be as huggy as I normally would because my arm is still sore, okay, from the needle . . . I'm a little more tired than I would normally be, all right. So therefore the energy, the enthusiasm is not at the level that it will be tomorrow, all right. (Participant N).

It's like after dialysis. . . Sometimes I'm up, sometimes I'm down, you know (Participant M).

My sexuality, you know, since I been on dialysis, something happened where I just can't perform anymore . . . (Participant O).

The first year – well, I was still kind of sexually active. I mean I would still enjoy it three, four times a week where as time went on, within the first year – the first year I was okay with it. The second year, it kind of dropped some where it started getting lesser like two times a week. Um, now where it – where dialysis now, my peak of that, it – it's – oh, God, how can I explain it? It don't be there no more like it used to. I mean, I have it in my head, but it don't work down there. (Participant S).

Similar to the men, female participants also admitted to a diminished physical sexuality state since starting dialysis. Only three women including the oldest I, the youngest E, and the one married participant R elaborated on the issue of diminished physical sexuality since beginning dialysis:

I used to have a sex drive . . . and it's just like once I started dialysis, I just don't have one at all. (Participant E).

Since being on dialysis, I don't have that feeling. Whatever that feeling is to make out with my husband, I don't have that. (Participant R).

Participant I reported “faking it” to maintain her relationship with her male partner. This participant's response suggested the image of a woman who perceived that females should be sexually submissive to their male partners. This view supported an endorsement of traditional masculinity and suggested that perceived expectations of their partner influence physical sexual behaviors for some women. During this participant's demographic data report, she related that

she was not sexually active or in a committed relationship. This difference in the participant's reports was not discussed with her and is suggested to further emphasize the tension associated with perceptions of altered sexuality.

Um, my [sexual drive] isn't as strong as it used to be, but I fake it, so it don't bother my relationship. I deal with it that way. (Participant I).

Male participants' reports of diminished physical sexuality included concerns about altered partner relationship and partner satisfaction. This element of concern corresponded to previous descriptions of "all man" roles as supportive of others. A primary concern expressed by five participants (B, M, N, O, and S) was to not "*hurt*" their partners as emphasized by the following response:

You know, in all fairness, I let her know, "Hey, I'm not what I used to be, Baby. This thing got me," and I have to do what I have to do. Sometimes I'm gonna be weak. Sometimes I'm gonna be strong, and sometimes I'm gonna just want to tell you go home anyway... I'm just not going to confine her to my life, okay. I do my little distance, you know. I don't want her to hurt. I don't want to hurt her. (Participant M).

Participants (B and N), both older males, indicated that relationships with each of their partners helped facilitate a general acceptance of their altered physical sexuality. Both participants reported recent sexual activity; however the last date of sexual activity for participant B was two months. Participant N reported last sexual activity as two days prior to the interview. Participant B reported being content with his physical sexuality, personal sexuality identity, and intimate relationship:

Well I mean, you know, like I say, me and my girlfriend, we all right, you know. And I even told my fiancée, I don't feel and she was like, it didn't bother her one bit [laughing]. And, you know basically, I felt more content. Because I was like, I really don't want to be that intimate that much, like I used to before I got on dialysis. (Participant B).

Participant N reported the use of communication and alternate forms of intimacy that are suggested to represent an adaptive strategy to minimize altered personal sexuality identity:

When I first had my fistula and started going through changes with dialysis . . . she didn't know what to do as far as, you know, where to touch me, you know, how to approach me,

what kind of mood . . . I definitely put my partner's needs in front of mine when it get to, um, the loving or physical aspect of our relationship because I get more pleasure seeing her satisfied than actually achieving satisfaction myself because that will, that will come. . . . the desire isn't diminished. Plus, you know, I love my wife, all right. I think she's the most beautiful woman in the world, and every time I look at her, I want her anyway. But I just know that it's just not to be, um, so we'll just do something like maybe just hold hands or, you know, or say things to one another, you know. I try to touch her with words . . . (Participant N).

Responses from the following two participants (O and S) emphasized potential effects of diminished physical sexuality on both personal sexual identity and on intimate/personal relationships for both themselves and their partners.

You get up and your other half can't get satisfied so she start getting attitudes and you know, things just start happening. So dialysis is really a drag, you know, and it's not fair to the other person, you know. (Participant O).

You know, I hear about a lot of people's relationships [that] go totally downhill after they get on dialysis. I know a lot of people that – their relationships – they be married and when they get on dialysis and that first two years, they divorced or separated because due to the fact that a lot of men, . . . they sexual desires goes away because of them being on dialysis . . . I mean when you're on dialysis, . . . it just don't function down there, and that's what actually gets me mad because I get upset sometime when it doesn't function right, and I have to take some medication and still wait 45 minutes . . . if you don't have a patient woman that don't understand what's going on with you, she gets upset about it . . . You know and a lot of women . . . don't understand that, and the first thing they want to do is say forget it if they can't continue enjoying themselves. They just say forget it. I don't even want to be bothered no more now, and it makes you, gets you in arguments. It upsets the house and . . . (Participant S).

Participant R, the only partnered and sexually active woman (per demographic data) also reported diminished physical sexuality. This participant identified greater maturity in her present stage of life as primary reasons for her altered sexual state. Similar to some of the partnered males, participant R indicated having a positive relationship with her husband and being content with her sexuality. Unlike the male participants, participant R did not express concerns regarding her partner's possible altered physical sexuality or personal sexuality identity.

I think where we are in life because, uh, you know. . . I think that's a mental thing, too, because I don't know. When we first got married, boy we used to go at it every day. Then I think maybe age because as time got on it wasn't no big thing. Okay if you want to, that's fine. If you don't, that's fine, too. (Participant R).

Three partnered male participants (N, O, and S) adamantly asserted that health care professionals should be aware of the mental and relationship strain associated with altered physical sexuality. According to these participants, health professionals place too much emphasis on sexuality issues as medical problems. Participants' responses further indicated that diminished physical sexuality encompassed more than absence of the physical sex act. A description of the mental strain associated with altered physical sexuality was expressed by participant S:

Well, me, I would want them to understand exactly what goes on with a person because for one, sexual. It's also a mental thing because it can be mentally real stressful and, I mean, that they don't understand that – to them it's just medical. It's not. It's physically. It's family oriented, because a lot of times, even when you're on dialysis, it breaks up home, and you got kids, you got a wife. It will break up your home if they don't understand everything that's going on. (Participant S).

The three participants (N, O, and S) also declared specific suggestions to promote health professionals' understanding of mental and relationship strains associated with diminished physical sexuality. Suggestions included asking specific questions regarding an individual's sexuality concerns, providing privacy to support communication, and extending an invitation to partners to discuss sexuality and other hemodialysis-related issues. These suggestions provided further indications of participants' degree of concern about altered partner relationships and partner satisfaction. Participants indicated a desire to discuss sexuality-related issues with health professionals and to have health professionals initiate these discussions.

[My wife learned] . . . mostly on her own. I mean she was willing to do that and what that showed me was her love for me. . . . I think health care providers should at times extend an invitation to the partners of the dialysis patients, the people who are going to . . . be with them at home, all right. I think they should extend an invitation to those individuals to, um, experience as much as possible firsthand as observers, all right, because there are things that – things that you can't really learn, you know. If – even if you just, you know, come to see or view what a dialysis session is like, then you could – you gain additional knowledge. (Participant N).

They need to come up with something to fix this thing because, uh, it kind of – you know the dialysis with the sexuality thing kind of tears up the relationship, you know. (Participant O).

I think that the husband or if they give the mate that's on dialysis some literature or something to bring home for that particular person to look at and understand what's going on where it will tell you that, you know, due to such and such . . . , sexual drive will drop,... which they can understand and see it in black and white instead of just telling them that. Because sometimes even though you tell your mate and that, and they don't see the literature on it, they will think that you out cheating . . . the doctors, the only way you meet with them in private if you go out to their office, . . . They come right to your bed [in dialysis center] and they talk to you if you need any medication. They look at your chart, look at blood work, what has been done on you and they try to adjust your meds and everything there, which that's not a problem. . . . but you know, they won't bring up about your sexuality (Participant S).

Despite the desire for health professionals to be involved in the management of sexuality issues, barriers were also acknowledged. Participant S's response was particularly insightful regarding potential barriers to discussions related to sexuality. This participant shared:

You feel less than a person when you talk about it [sexuality problems], you know. You feel like you're not that particular man because things is going wrong with you, which – that's not to your fault, but now you sick where things is happening to you and you never was expecting to have happen to you . . . (Participant S).

The response by participant S reflected a considerable degree of mental strain associated with his perceptions of a diminished sense of who he was as a man. The response further reflected an endorsement of traditional masculinity that supported “shame” in admitting to a loss of perceived normative male roles or of sense of “who I am as a man.” Additionally, this response indicated that the avoidance of discussing sexuality issues does not necessarily indicate the absence of these issues. Nor is the avoidance of discussing sexuality issues an indication of not wanting to discuss these issues.

Participant O asserted that his diminished physical sexuality state was associated with an erosion of personal sexuality identity or who he perceived himself to be as a man. This participant reported a live-in relationship of 20 years and a history of impotency for the past 2 years. Length of dialysis time for this participant was 4 years. This participant's response indicated anger at his stated inabilities and even envy of his son based on his perceptions of the importance of a man's ability to perform sexually:

I feel less than a man because I can't perform as a man. I can't measure up. You know, like my son. My son don't have nothing wrong with him. So I'm sure he's a full man. I mean, you know, because when you – when your sexuality is at risk, it's like you're not a whole man, you know. It's just, I don't know. I don't know what else to say except it's just; you're not a full man. At least that's how I feel. I'm quite sure other guys that's going though the same thing feel the same way, you know. (Participant O).

Although Participant O contradicted the other participants, this participant continued to support the view that diminished physical sexuality affects more than physical sex. This participant's response suggested an overly strong endorsement of a prescribed role of men that included the ability to sexually perform. Evidence of the influence of this endorsement was strongly reflected in participant O's negative responses which implied ineffective adaptive responses due to his perceptions of inability to maintain a “normal” level of manhood.

In comparison to the married/partnered participants, the single non-partnered males (C, L, and Q) declared that dialysis did not have an effect on their sexual drives. However, the same men reported that the hemodialysis regimen is viewed as a deterrent to steady relationships. Participant C spoke of not accepting his limitations as a man since dialysis (e.g., inability to be the provider). Two participants (L and Q) denied the effects of dialysis on their physical sexual ability, but suggested that dialysis is viewed as a barrier to a committed relationship. These latter views supported the implication that diminished physical sexuality is linked closely to an altered personal sexuality identity, altered intimate/personal relationships, and potentially altered family-social role functions.

I'm the type of man . . . I don't feel that I'll be eloquent enough that I can support [financial] a relationship, you know. Even though, she may accept me, who I am, but I won't accept myself and I got a problem with that. (Participant C).

It [dialysis] hasn't affected the [sexual] drive. . . . one of the things it did do was make me change my lifestyle in the sense that I said I was not going to have sexual intimacy until, unless I was in a relationship . . . [dialysis] plays a huge part in the sense that, I don't want to be, um, a detriment to someone, you know, there's sometimes a feeling of hesitancy about getting involved with someone (Participant L).

I'm sexually active, you know . . . I have some females that I talk to from time to time, but one of the reasons I'm not in a relationship . . . might be the fact of this dialysis, and know that they're not attractive to that. (Participant Q).

Responses from female participants regarding their perceptions of dialysis on their physical sexuality differed from male participants. All but one of the women (participant R) indicated that diminished energy, personal fear of being a burden, concerns expressed by a previous partner, and not having the right partner prohibited intimate/personal relationships more than their diminished sexual drive. These factors implied greater concern regarding an erosion of personal sexuality identity, intimate/personal relationships, and possibly family-social roles as women than their concern about physical sexuality.

I don't have enough energy to be involved with a relationship because of the zapping that dialysis does. (Participant A).

I think that's part of the reason why me and my old man broke up, you know. He couldn't stand the fact that I was on dialysis. . . He went through dialysis with his mom. He didn't want to go through it with me too. (Participant G).

I haven't had a relationship for a couple of years. I don't really think it's, if I were with the right person that it would make a difference. (Participant J).

If I was in a relationship I probably would be more of a burden on my spouse or partner than to contribute to the relationship. They would more have to wait on me or, you know, if I'm not feeling good, you know, you don't want nobody to touch you, have sexual contact. (Participant K).

Theme 3: The hemodialysis regimen is an emotional rollercoaster. Actual or possible erosion of sexuality has been linked to many hemodialysis-associated stimuli or stressors. Explicit and varied emotions associated with the hemodialysis regimen were described by 12 participants (7 males and 5 females). Participants' emotions were in response to the initiation and daily challenges of dialysis; difficulty accepting dialysis; loss of time, energy and independence; and loss of personal control.

Passionate emotional responses to the initiation of dialysis were described by five participants (A, B, K, M, and Q). These emotions were described as feeling like the "rug [was]

pulled from beneath me,” “thought my life was over,” “being on death row,” and “depression.” Another emotion, fear, experienced during hemodialysis treatment was described as “every bell I heard and every button they pushed.”

The three male (B, M, and Q) and two female participants (A and K) who elaborated on these initial emotions reported being on hemodialysis therapy for 5 or less years. Difference in ages did not appear to be associated with the described negative emotions. Involvement in a relationship and/or having strong connections with other support systems at the initiation of dialysis also were not associated with emotional rollercoaster effects of hemodialysis. Responses by these participants indicated that the most intense negative emotions often occurred during early stages of the hemodialysis regimen. These emotions were suggested to potentiate early erosion of personal sexuality identity:

I found out that I had to be on dialysis and I felt like I had been punched in the stomach and the rug pulled from under me. (Participant A).

My doctor told me about 10 years ago, that I was going to end up on dialysis. I thought my life was over . . . I was like 19 or 18 years old, you know and I didn't understand it then and it scared me. (Participant B).

When I first started dialysis, I was up. Every bell I heard, every button they pushed, I wanted to know what, why, how, and you know . . . I just recently started going to sleep while I'm on dialysis. (Participant K).

For a while I did have a little bit of depression about this. I said, Wow, this happened to me . . . two days after I found out, I was scared. I mean I was scared. I couldn't sleep. What am I gonna do? Shoot, what, it's been a mess, though, but like I said, I'm not scared no more. (Participant M).

I was actually thinking, Okay, I'm on death row. That first year you go through some things. You're like, Wait a minute, God doesn't like me. He doesn't want me around for much longer. So I wasn't saying I was ready to die, but I was seriously thinking that there's a good chance I wasn't going to make it. (Participant Q).

In contrast to these responses, participants G and N also acknowledged having rollercoaster responses to the initiation of dialysis. However, this older female and male

participant indicated that their emotions were modified through the aid of strong support systems (i.e., God and partner support). This modification process was suggested to minimize or prohibit a loss of personal sexuality identity:

The routine was something that required some adjustment, um, and I don't find it – I don't find it difficult now because my partner and I have gotten into, uh, I guess a routine, no, not a routine but acceptance of what hemodialysis actually does to me physically. (Participant N).

Participants' responses also indicated that the acceptance of dialysis regimens and reports of a less altered sense of “who I am as a man or woman” should be interpreted with caution. The ongoing rollercoaster effects of dialysis regimens have been suggested to be substantive stressors to which some individuals never fully adapt or regain a satisfactory sense of “who I am:”

Sometimes it gets hard trying to put the place for dialysis in your life, but it comes after God, you know. It has got to come after God, 'cause that's what keeps me living. (Participant G).

Three participants (E, J, and O) described their emotional responses to the hemodialysis regimens as continuous, daily challenges. Among these participants, E and J were the youngest, both women and not involved in intimate relationships. Participant O, an older partnered male expressed the greatest concern regarding his altered physical sexuality state [detailed earlier]. Length of dialysis for these participants ranged from 3.5 to 7.5 years. Participant E description of hemodialysis as an experience that required mental preparation before each dialysis treatment best illustrated continued emotional response to hemodialysis:

You have to get yourself prepared to go to dialysis. You just can't get up, Oh, yeah, today is a dialysis day. He-he-he., I mean, you know what I'm saying. I'm not making light of it, but you have to really get in your head . . . (Participant E).

Despite attempts to mentally prepare for the hemodialysis regimen and recognize its value, the participant O, along with C (older divorced male) and J (younger single female) suggested that emotions pertaining to being “*overwhelmed*,” the reality of “*bad days*,” and just having to go “*through this [dialysis] the whole week*” makes acceptance of the dialysis

experience more difficult. The difficulty in accepting an experience that is also acknowledged to be essential for life heightened the experience as being an ongoing rollercoaster that is suggested to alter an individuals' sense of "who I am as a man or woman." Length of dialysis for these participants (O, C, and J) ranged from 1 to 7.5 years.

Then the next thing you know, they says, uh, got to put you on dialysis. I said, "Wow" (quieter and with expression), you know it blew my mind. . . . I'm still trying to deal with it, I accept it a little bit, cause I'm on it, but I hate it. . . . Man, I hate it, I really hate it, when I go to bed, I be so glad when the week ends, man, I get two days off. Then when Sunday comes around, I got to go through this again. I would rather go to a job, let me go to work, I got to go through this for a whole week. (Participant C).

Sometimes you feel overwhelmed and you just want just to get off the dialyzer, just I need to cut my treatment point blank because it's overwhelming till you just want to get away from it for just a minute, but you know you got to come back to it. (Participant J).

You know, but you still got to get up every other day and push yourself to go and then when you, when you – on the bad days when you have a bad run, you just be so fatigued and you know, it's just a nightmare, you know, because one day I left out of there, I thought I was really gonna die, you know, I'm – my heart was beating slow, blood pressure was low. Scared me up that day. (Participant O).

The rollercoaster effects of hemodialysis also included participants' reports of loss of personal time, loss of energy, and loss of independence – all of which were described as factors that alter perceptions of who they were as men and women when compared to each of their pre-dialysis states. Time commitments included travel to and from the dialysis centers, placement and time on the dialysis machine, and time that is required for individual monitoring after their removal from the dialysis machines. The commitment for actual time on the hemodialysis machine ranged from 4 to 8 hours for all participants. Though concerns of loss of personal time, energy, and independence were expressed by nine participants (from both genders and of varying ages), the following responses from three older participants emphasized this concern:

Well, I am jealous of them [people who are not on dialysis], envious of the fact that they have all that extra time and that part of their life. . . . I guess the major downfall of being on dialysis is having to sit in that dialysis chair for 6 to 8 hours, like being a prisoner. (Participant A).

The only thing is, uh, day after tomorrow I got to be at dialysis. So whatever we got to do, it got to happen between the time I leave and the time I got to go back day after tomorrow. (Participant F).

Well, if I wasn't on dialysis now . . . , I'd probably be working and be out there like the average man, you know. But, uh, I still don't see no difference. The only difference is I got to keep living. I got to go to dialysis treatments three days a week. (Participant H).

Despite the challenges of hemodialysis, both male and female participants (n = 10) acknowledged that this treatment was necessary for a lifetime. The acknowledgement of dialysis as a lifeline amidst its challenges is suggested to further reinforce the emotional rollercoaster effects. This view was expressed by older male and female participants (all but one participant was 50 years and older). Perceptions of dialysis as a lifeline were suggested to promote positive adaptive responses to the hemodialysis regimen as exemplified by the following participants:

I feel a lot better physically since starting dialysis . . . (Participant A).

This is for your health, how can you walk away. (Participant B).

I've fitted it [dialysis] into my lifestyle. I don't even look at it as a hindrance. It's keeping me alive. (Participant I).

I'm glad to be here, okay. He [God] didn't put me out. He put me on a machine okay. I'm glad to be here. If that's what's gonna keep me here, let's do this . . . (Participant M).

However, male (C and O) and female (E and G) participants who had reported negative descriptions and responses to demands of dialysis also were referred to dialysis as a treatment that "had to be endured."

Matter of fact, the only way, I'm going to stay alive, so I got to go . . . (Participant C).

This is saving your life. So you, you try to put up with it ... you sit there and you endure because you know this is your life. (Participant E).

At times it be tiresome, you know. I don't feel like going, you know, and I know I have to go. If I skip, if I don't go, I'm gonna get sick. (Participant G).

You know it's keeping me alive so I got to – I can't knock it all the way because it is keeping me alive. Without it, I'd be a dead man, you know. (Participant O).

The ability to continue providing support for one's family was acknowledged to be a benefit of dialysis therapy. Additionally, compliance to the dialysis regimen was reported as a testimony to personal recognition of the importance of dialysis as indicated by the following two older male participants:

I have to take care of myself in this dialysis cause I got family members that depend on me still. (Participant F).

Dialysis is my lifeline, all right. Without keeping my regular schedule, I wouldn't be able to contribute to the community or the family unit. (Participant N).

Despite an awareness of the importance of the dialysis regimen, four participants (A, F, M, and R) admitted to making potentially harmful decisions to regain a sense of control – thus maintain “who I am as a woman or man.” Loss of control is also closely linked to the demands (stressors) of hemodialysis. Loss of personal control is suggested to be associated with perceptions of altered sense of who I am as a man or woman. Reports of measures to regain control included missing a day of dialysis and eating prohibited foods. Participants who reported taking measures to regain control also indicated “*not blowing ... [the measures] all out of proportion.*” Therefore, these measures of taking control were viewed as being compliant to the required hemodialysis regimen. The number of years on dialysis ranged from 2.11 to 10 years for participants (A, F, M, and R) and was not indicated as a factor in making alternate decisions regarding the dialysis regimen.

I felt that I have taken a little control of my life back by refusing to do it [allow measurement of standing blood pressure], and being obstinate makes me feel a little more powerful, because ordinarily, I feel powerfulness when I'm there [dialysis center]. (Participant A).

I hear a lot of people say they're afraid to miss dialysis and it's not that I'm afraid 'cause I actually believe that I can miss on a Thursday because I can go back Saturday. (Participant F).

Like some Wednesdays, I'm just not up to it after dialysis, and then they'll call me, “Well you coming in Thursday?” Well you just took everything from me Tuesday and I ain't even built it back up Wednesday, you know. So, yeah, I might skip a Thursday. I say, I'm

gonna eat what I got to eat. I'm gonna eat what I want to eat. I may not eat a lot of it, but at least I had what I want. That means that I'm dictating my life. . . . I'm dictating my life, not this machine, not my doctor. They tell me what I'm supposed to do, but I do what I want to do and I do it the way – it's limited. It's not – I'm not blowing it all out of proportion. (Participant M).

Participant R's response is a further indication of measures that some individuals are willing to take to maintain a sense of control. This participant's response also suggested limited knowledge regarding preplanning and scheduling of hemodialysis therapy in locations away from home.

When I used to go on my vacation, you would have to set up, you know, for you to do dialysis down there. I never did that, . . . I would go to Mississippi – I'd drive there and we'd spend the week there and I would do no dialysis, none at all, . . . I did that I think for three years. I would go once a year. They'd be so mad at me. . . . I don't know why I don't set it up down there. I think because it's either expensive or I never did it before. I just never did it, but usually you'd have to pay up front for dialysis down there, wherever that is. You would have to pay up front. That's mostly maybe a hundred or something dollars up front, and I would never have it because that would be part of my spending money. So I wouldn't do it. . . . this white boy named . . . always told me, “. . . , if you get in trouble or you feel sick, just go the emergency room and let them know and they'll dialyze you and charge it to Medicare, to your insurance.” . . . so, I always had that in the back of my head. (Participant R).

Negative aspects of dialysis center staff and environment were also reported to be a source of the emotional rollercoaster effect of hemodialysis. Psychological support systems for the patient on hemodialysis therapy include health professionals and paraprofessional staff working in the dialysis centers. Most participants in this study provided positive descriptions of the healthcare staff (i.e., “fair treatment,” “caring,” and “wonderful”). However, several participants (n = 8) expressed concerns regarding the lack of positive mental support from dialysis center staff. The following thought-provoking response was related by Participant (L) who was on a home dialysis program. This male participant reported having a graduate degree and was employed as a counselor for young men and women:

I think centers are a huge problem. The reasons that patients don't do well, I believe, is that the environment is not conducive for a positive mental attitude and the negativity is so pervasive that people get wrapped up and caught up in that negativity and it brings

those who would be positive down, and the reason that I've been able to stay as healthy as I am is because I've spent so little time in a center. Had I spent the last seven years going to a center, I wouldn't be sitting here right now. It's just no way in the world, because I know as hard as I would have fought it, eventually that attitude would have somehow invaded me. So I think there's a big problem and a lot of that comes from not only other patients, but staff. They kind of, they kind of perpetuate that attitude.

And I think that's why we have patients that don't do as well as they could do because of the mental portion of it, not even necessarily the physical. The physical of course is a great portion of it, but I think the mental is just as important, and in some cases even more important. (Participant L).

This participant suggested that both staff and patients had a role in establishing negative environments in many dialysis centers. Additionally, he suggested that the length of time in negative dialysis center environments resulted in loss of one's sense of self.

They're [dialysis centers] in predominantly African American areas where they're [the residents of the area] lower income, lower educational level and they treat the patients like that, like they don't have a good knowledge of what's going on with their bodies and what's going on with their disease, and they treat them not as well as I think they probably should . . . , yet the patients, because they are not very proactive in their care, don't ask for anything more, don't require anything more, . . . I was able to do some things a little differently than some patients may have been able to do, but if you're in that so long, even you lose the battle. (Participant L).

Descriptions of negative dialysis center environments were emphasized by four males (C, N, P, and Q) and three female participants (A, G, and J). These participants were of varying ages, marital and sexual relationship status, and years of dialysis. The negative descriptions focused on unprofessional staff roles; perceptions of staff indifference; a lack of personal caring among dialysis staff; and lack of awareness of what it is like to be on dialysis. Negative experiences in dialysis centers are suggested to "break you down" or diminish effective coping processes and the sense of "who I am as a man or woman."

And they [dialysis staff] don't always do what they are supposed to do. . . . There are certain procedures that they are supposed to follow that are totally ignored. They are supposed to ask you, how you feel since your last treatment. . . . And it's not always their fault, because they are so few. And I know this is not true at every dialysis location... (Participant A).

I'm going to be honest with you; they [doctors] don't do nothing. All they do is write prescriptions. When the doctors come into the center to check on their patients, 'How you

doing? Do you need a prescription? That's it, they don't ask any concerns about what is going on or nothing like that. You know, the counselors, the nurses, they act like they don't care, just a routine thing for them. (Participant C).

They need to be a little bit more patient with people and learn to understand. . . .they don't seem to have compassion. They don't seem to have it. They just don't care . . . You know, it'll break you down. (Participant G).

They, uh, it's, oh it's so hard to describe. Um, just, uh, it's the way they carry themselves, the way, they, their attitude . . . some of them don't realize that with your illness that sometimes it changes the way you respond to people and some don't have good attitudes to deal with . . . they [people on dialysis] feel like they losing time out of their life, and then you go to a clinic where you might have a nurse or one of the techs, even the doctor, treating you like a child . . . they can't really know because they're not, they don't have dialysis. So they don't know how I feel and I guess to have more patience, more meekness. I think how would they feel if they were taking dialysis and I was giving you the treatment. Maybe they can get a better understanding. (Participant J).

I feel like they should be more open. Like I go to the clinic and some of them are not, don't want to give you the answer . . . They're not open . . . They're so distant and that's bad. I feel like we going through a mind thing . . . I think they [dialysis staff] should talk, be more – see what – how that patient is expressing himself and how they're treated. I think that they should come and spend some time with them and question them about, Do you feel like they are treating you right? Are you getting the service? How do you feel? Are they talking to you about positive statements instead of making negative statements to you? They don't do that. (Participant P).

Participants were eager to remind health professionals that they were in the dialysis centers because they had to be and “wanted to have a good day.” An expectation of having compassionate treatment and care from professional staff was suggested as an essential factor for having a “good day.”

There are some health care providers – technicians, nurses, who have a tendency to treat dialysis patients like they're kids . . . The communication, all right, from them to us, uh, is sometimes lacking . . . I'm not saying they should be empathetic or anything like that, but they definitely need to be a little more understanding, um, that there's a way to talk to people. If you're having a bad day, then go home. But we're there because we want to have a good day, all right. So just realize that. (Participant N).

Additionally, participant Q's response implied that dialysis center staff do not always identify individuals experiencing dialysis as men and women who experience “normal” male and female emotions.

The reason a lot of time, they're [dialysis staff] indifferent, because the mentality is, Oh, you're on dialysis. (Participant Q).

The foregoing responses imply that unprofessional attitudes manifested by dialysis center staff are viewed as additional stressors that have negative effects on dialysis patients' individual perceptions of "who I am as a man or woman." To elicit further responses regarding the dialysis center environments and the influence of racial identity on perceptions of sexuality, participants were asked: "Do you think that any of the concerns that you have mentioned would be different if you were not African American?" Several men (n = 6) emphatically stated that color barriers did not exist. Most women participants (n = 5), though not as expressive, also supported this belief. Assertions were made that kidney failure and the dialysis machines do not discriminate. The positive reports of "no color barriers" were noted to be a different perspective from previous negative reports associated with dialysis centers' staff and environment. The following responses suggest that most African American do not openly associate their ethnicity with dialysis associated sexuality concerns:

There ain't [sic] no prejudices there, as matter of fact, ain't [sic] no color barriers there, we all dealing with the same thing. (Participant C).

It [dialysis] ain't [sic] got nothing to do with being Black. There's White folks on dialysis, there's Chinese, there's every kind of nationality on dialysis. There is kidney disease everywhere. (Participant D).

I don't think being White or Black has anything to do with me as a man or a person being any different. (Participant F).

The machines don't discriminate. Its [dialysis machine] gonna clean whoever they put on it, you know. (Participant H).

You know, the hypertension, diabetes, and maybe there's some additional things that maybe people of other races don't have. But other than that – that machine don't know what color – all it knows is blood red. (Participant L).

No, I don't think color or gender has anything to do with it, you know. ... they [sic] kidneys go out just like ours. (Participant O).

Theme 4: Only people experiencing dialysis understand. Participants in this study, similar to other people experiencing hemodialysis treatments spend long hours in dialysis centers. Consequently, individuals who are experiencing dialysis within the same centers are suggested to play important roles in each other's lives. Participants in this study related the importance of family, friends, and God. However, the prevalent theme suggested by participants' responses was that "only people experiencing dialysis understand." This acknowledgement was made in spite of most participants' report of few official mutual support groups within each of their dialysis centers.

Both male (C, M, and S) and female participants (E, G, J, and K) expressed the importance of friendship and support from others who had similarly experienced hemodialysis. Other people undergoing similar experiences were indicated as the best source of support, motivation, and information pertaining to hemodialysis-related issues. Mutual support groups as described by these participants can promote positive coping and adaptive responses to hemodialysis-associated stressors that affect sexuality.

Positive descriptions of mutual support groups were shared by both single and married participants. Participant C who reported greater perceptions of isolation from his family and friends indicated that dialysis is different than other experiences. This response further supported this participant's perceptions of not being like "normal" men.

We [people on dialysis] on a different life, different thing from everybody else cause they can relate to what I'm talking about. (Participant C).

Women participants (E and J) reported hemodialysis as a daily challenge and feeling depressed while participants G and K also stressed that they could best communicate their emotions and dialysis concerns to other women experiencing dialysis: These responses further reflected challenges associated with the hemodialysis regimen and the potential to erode one's sense of "who I am as a woman."

We [people on dialysis] can relate to what's going on with one another more than a person that's looking in; that's not getting stuck three times a week. We know how the pain is . . . people that don't go, they be like, Oh I know how you feel. You couldn't. Until you're in that situation, you can't know how I feel. Like when you lose someone close to you. If you still got your parents you can't say, "I know how you feel," You have your parents. You see them, you speak to them, you do whatever it is. So you can't relate to me, but another person that lost their mother or their father or both, they can relate. (Participant E).

I made a lot of women friends at dialysis, since I been going to dialysis, you know, and that's my outlet of getting some of my, my, my sadness off, you know . . . I can communicate with them about dialysis. My neighbors and stuff, they really don't understand it. I can't communicate with them like that, you know. Sometimes like when I get off the machine, I sit around just to talk. (Participant G).

It's weird, you know, that you can, when you're sitting there, it's different when you're talking to a doctor. You don't tell him the things that you tell somebody else that's going through the same thing . . . I would never have started it [dialysis] if it hadn't been for a friend of mine. She talked to me every day because she knew someone that was on dialysis already . . . (Participant J).

I have two women friends at dialysis. They give me motivation and they've been on dialysis longer than I have and they know what I'm going through since I'm just starting dialysis . . . my sister said, well we understand you're sick. You know, we sick too. But they're not sick to the point that they have to go to dialysis three days a week or feel fatigue or . . . (Participant K).

Despite having supportive families, partnered male participants also elaborated on the benefit of mutual support systems.

Sometimes people need to talk it out, you know. They need to get somebody to just – not force them to talk it out. Just take them in and put them on the side of a buddy, you know. I know each and every last one, what to do to make them laugh, and they know what to do to make me laugh. I like that, you know, and that takes a lot of stress out, that does. (Participant M).

You know, people on dialysis understand that because they go through it. They go through it three days out of a week. People that don't have those physical problems, they don't understand that . . . some people at the, at the clinic, they don't have a support system at home. They don't – some of them don't have anybody really, you know . . . so when they come down to dialysis, that's basically the only kind of support that they have or people to talk to about they [sic] problems because it's basically – I mean you part of they [sic] family because you're there four hours a day. So it's like half your day there. So it's just like having a – basically a support family down there . . . (Participant S).

Contrasting views of relationships among individuals on dialysis and of dialysis center mutual support groups were offered by two older male participants (F and N). These participants reported being married and having strong partner and family support systems. These views suggested that likely various degrees of mutual support were required and sought by dialysis patients who were treated in dialysis centers:

I think I'm a little better off than most men on dialysis . . . I got a lot of friends [at the dialysis center], right, but we are friends out there. . . . I don't frequent people's [from dialysis] homes because . . . my family's private to me. I don't bring people – I'm saying men and women – I don't bring people, a lot of people to my home. This is private and I protect them, and we can be best of friends but I don't run in and out of your house and I don't want you running in and out of mine . . . I keep my friends out there . . . you know what I know about people on dialysis is what I see at dialysis. (Participant F).

I went to a couple of support groups and some support group functions, and the only thing that I found there . . . not the only thing, but people complaining, all right, about this isn't right, that isn't right and all, and I don't need to be around miserable people. So I tend not to, um, well go to support group functions or join support group. (Participant N).

Mutual support groups are suggested to have a positive effect on sexuality for people receiving hemodialysis. Such groups are implied to be most beneficial for individuals who are new to the hemodialysis experience and who have limited family or other personal support systems. Based on participants who expressed concerns about mutual support groups, it also is suggested that mutual support groups be professionally facilitated.

Summary

Four themes emerged from participants' descriptions of perceptions and behaviors pertaining to sexuality. The first theme was identified from the participants' beliefs about gender roles and the influence of these beliefs on perceptions of sexuality: endorsement of gender ideology influences perceptions of sexuality. The second theme emerged from participants' concerns regarding physical sexuality: diminished physical sexuality represents more than the physical sex act. The third theme emerged from participants' perceptions and responses to

hemodialysis associated stressors: the hemodialysis regimen is an emotional. The fourth theme identified by participants' perceptions of mutual support systems within dialysis centers was that only people experiencing dialysis understand.

Male participants' descriptions of "all man" and of sexuality-related stressors and responses since being on dialysis revealed varying degrees of an endorsement of traditional masculinity ideology. In comparison, single-parent females reported a primary concern about altered mother/caregiver roles which are suggested to reflect an altered image of being a "strong" woman rather than an endorsement of traditional femininity ideology. Beliefs about prescribed male or female roles were found to influence perceptions of sexuality for both of these groups. Though, evidence of clinical depression was not found, two women participants reported depressive symptoms that contributed to their emotional states as a loss of "all woman." This "loss" was suggested to be a negative adaptive response to the perceived limitations of "who I am" as a woman.

Physical sexual ability is indicated as an important characteristic for men who endorse traditional masculinity and was noted to be a primary concern for a majority of males in this study. However, partnered males were just as concerned about altered partner relationships as their own diminished physical sexuality. Strong assertions were made regarding roles that health care providers should take in helping "fix" issues associated with altered sexuality states. Single, non-partnered males declared that dialysis did not have an effect on their physical sexuality, but admitted that dialysis was a deterrent to steady relationships.

Female participants also reported diminished physical sexuality. However, most females indicated that their diminished physical sexuality was less a deterrent to a steady relationship than factors, such as: diminished energy, personal fear of being a burden, and not having the right partner were greater deterrents to intimate/personal relationships.

Both male and female participants described the hemodialysis regimen as an emotional rollercoaster. Intense emotions were associated with initiation and early experiences associated with this regimen. These emotions included: fear, hate, being overwhelmed, and a loss of personal control. Such intense emotions suggested a risk for greater erosion of personal sexuality identity and family-social roles as men and women during early stages of dialysis. Older male and female participants often viewed the hemodialysis regimen as a persistent and daily challenge that required mental preparation before each dialysis day. Risk of an altered sense of “who I am as a man or woman” was suggested to be even greater for these participants.

Despite descriptions of hemodialysis as an emotional rollercoaster, older participants were more likely to identify dialysis as a critical lifeline and support to daily health. However, the need for this lifeline and the endurance of stressors associated with it appeared to be a continuous source of conflict for some participants. This conflict is suggested to amplify perceptions of altered sexuality, thus potentially promoting ineffective coping and adaptive responses.

Several male and female participants identified unprofessional staff as contributors to the emotional rollercoaster effect of dialysis. Negative dialysis staff and center environments were suggested to further erode perceptions of sexuality for individuals experiencing dialysis. Racial identity was not attributed to dialysis-associated sexuality concerns. Participants however expressed a desire to remind health professionals that individuals experiencing dialysis were in the centers because they had to be there. Participants declared that they desired and expected companionate treatment from health professionals and to have a “good day.”

Family and God were acknowledged as key support systems. However, many participants viewed other patients who had similarly experienced dialysis as being the only ones who understood what it meant to be on dialysis and its effects on them. Despite these views of other

dialysis patients as essential support systems, most participants reported a lack of official mutual support groups within the dialysis centers where they were being treated.

CHAPTER FIVE

Discussion

The purpose of this qualitative study was to explore African Americans' perceptions of physical sexuality, personal sexuality identity, family-social roles as men and women, and intimate/personal relationships since being on hemodialysis. Data from this study contributes to nursing knowledge in four areas, including understanding: (a) how the endorsement of traditional gender ideology influences African Americans' perceptions of sexuality, (b) that diminished physical sexuality represents more than the physical sex act, (c) the influence of other hemodialysis associated factors on African Americans' perceptions of sexuality, and (d) the importance of applying a holistic framework to assess multiple aspects of sexuality for African Americans who are experiencing hemodialysis.

A discussion of the four themes; (a) endorsement of gender ideology influences perceptions of sexuality, (b) diminished physical sexuality represents more than physical sex, (c) the hemodialysis regimen is an ongoing rollercoaster, and (d) only people experiencing dialysis understand; that emerged from this study is presented in this chapter. This chapter also includes a discussion of the application of the guiding theoretical framework; strengths and limitations of the current study; implications for clinical practice and future research; and conclusions.

Endorsement of Traditional Gender Ideology

One important finding from this study that can contribute to nursing knowledge is a deeper understanding of the influence of traditional gender ideology endorsement on African Americans' perceptions of sexuality. The male participants in this study characterized sexuality according to an endorsement of traditional masculinity ideology. This finding is consistent with previous reports of a greater endorsement of traditional masculinity ideology by African American men than either Caucasian males, or Caucasian and African American women

(Levant, et al., 2003; Levant & Majors, 1997; Levant, Majors, & Kelley, 1998). Traditional masculinity ideology refers to the endorsement and internalization of male roles that include being a supporter, dependable, physically strong, independent, and having drive and desire for physical sex performance (Pleck, Sonenstein, & Ku, 1993).

The strong endorsement of traditional masculinity ideology by African American men has been associated with a need to preserve an image of being “all man.” Preserving this image by looking and acting normal was noted to be an important coping strategy for the study’s male participants. This strategy included a focus on their ability to handle anything despite potential barriers. For example, one participant maintained this ideology by asserting that dialysis was not a barrier to his supportive role as husband, father, grandfather, and to the family pets: *“I can do the same thing they [other men not on dialysis] do.”*

Despite the arduous nature of hemodialysis, many male participants reported ongoing behaviors associated with family-social roles. Responses such as *“I take care of my family. . . I do what I’m supposed to do as a man. . . .”* suggested that sexuality represents more than physical sexuality or personal identity and reflects an interconnected process for African American males. These findings support earlier studies exploring the meaning of manhood among African American men in which relationships with others were strongly associated with traditional definitions of manhood (Hammond & Mattis, 2005). Perceptions of looking and acting normal within prescribed male roles were suggested to increase these participants’ sense of “who I am as a man.” For the majority of male participants, the focus on continuing to be able to support their families is suggested to represent coping strategies that minimize feeling less than “all man.”

Additionally, four men in the study asserted that they did not compare themselves to others and/or were “better off” than other men on dialysis. Threats to the image of being a

“normal” man are suggested to be important for African American men who experience the mental and physical challenges of the hemodialysis regimen. Assertions of behaviors that represent being “all man” are suggested to be forms of coping and adaptive strategies. These strategies were noted to be similar to the “cool pose” strategies identified by Levant and Majors (1997) and Majors and Billson (1992). Cool pose strategies refer to adaptive responses to socioeconomic and racism barriers among males within the Black urban culture. These strategies are suggested to provide a sense of control and confidence in environments characterized by socioeconomic and educational disadvantage and barriers to traditional masculinity ideology. The utilization of similar coping strategies among African American males who experience hemodialysis are suggested to minimize perceived or actual limitations that imply being less than a man.

This study also supports findings of previous studies indicating that the degree of individual endorsement of traditional masculinity varies and is dependent on a variety of contexts (Addis & Mahalik, 2003, Hammond & Mattis, 2005, Phillip, 2001, Wade, 2008). Specific context is linked to each individual’s definition of masculinity and to broader cultural, social, economical, and political influences. The internalization of the position that the “all man” should be able to handle anything is suggested to substantially affect men who possess fewer effective coping processes (e.g., men with physical or support limitations).

An example of differences in degrees of traditional masculinity endorsement was demonstrated by male participants in this study. The majority of male participants who reported having diminished physical sex drive and ability also reported satisfactory adaptive responses (e.g., feeling content in present relationships). However, one participant, who reported being in a relationship for 20 years and a two-year history of impotency strongly declared feeling less than a man when confronted by diminished physical sexuality. His assertion supported Tepper’s

(1999) suggestion that a comparison of perceptions of “who I am” to society’s construction of what constitutes being a man (or woman) can result in a loss of manhood (or womanhood) if the labeled “me” cannot be reconciled with other social identities. Addis and Mahalik (2003) similarly observed that men who perceived problems as non-normative have greater risks to their self-esteem. These findings argue for understanding sexuality from the perspective of each individual. The findings also support assessing sexuality beyond the narrow linkages between hemodialysis and altered physical sexuality of dialysis patients (Stewart, 2006).

In contrast to male participants, responses from female participants did not reflect a fixed endorsement of traditional femininity ideology. Traditional femininity ideology refers to a system of beliefs that women’s lives are fulfilled by selfless roles as nurturers and caregivers in society. Traits that are attributed to an endorsement of traditional femininity ideology include pride in feminine appearance, appearance of the home (Rouse-Arnett, Dilworth, & Stephens, 2005), and emphasis on motherhood (Choi, Henshaw, Baker, & Tree, 2005). These traits support perceptions of respectability, which are suggested to represent a sacrifice of sexuality (Wyatt, 1997). Furthermore, the endorsement of traditional femininity ideology is suggested to support the image of the stereotypical “mammy” or long-suffering maternal figure (Beauboeuf-Lafontant, 2003).

Primary concerns by the women in this study included an alteration of body image secondary to disfiguring scars and disruptions of roles as mother/caregiver associated with other losses. While these concerns initially suggested an endorsement of traditional femininity ideology, participants’ descriptions of their dialysis scars and their disruptions of their mothering role were more complex than a narrow view of traditional femininity ideology. These dialysis regimen effects on sexuality exemplify multiple losses to their views of “who I am” as women; the losses included loss of time, energy, and independence associated with the regimen. These

losses appeared to be related to an erosion of “who I am” that exceeded female participants’ perceptions of their physical beauty. Single mother’s descriptions of the effect of the hemodialysis regimen on their parenting roles were even more passionate. Their descriptions suggested major alterations of their roles not only as caregivers, but also as primary support systems and providers for their families. These participants’ descriptions appeared to be associated with the notion of the “strong” Black woman. In contrast to the image of mammy, these women are suggested to portray “mules” who despite being overburdened, attempt to assume additional responsibilities for others (Beauboeuf-Lafontant, 2003; Wyatt, 1997). For these women, perceptions of inadequacy and inability to continue responsible roles suggested a strong influence on their perceptions of altered sexuality and could potentially erode their sense of “who I am as women.” The following emotional response by one participant illustrates this sense of inadequacy: *“It [dialysis] has changed me as a mother tremendously because I cannot take the stress. I’m more focused on, uh, dialysis days and non-dialysis days, and pretty much my youngest have gotten away with a whole lot that the older ones didn’t get away with . . .”*

This research supports Cole and Zukers’ (2007) study of Black and White women’s views of dominant femininity. Cole and Zuker found that Black women rated feminine appearance of clothing and home higher than White women, but were also found to be more likely to identify as feminists. Cole and Zuker suggested that Black women have a greater sensitivity to experiences of racial and socioeconomic oppression than White women. Furthermore, these findings suggested that Black women’s construction of sexuality are not limited to their identity as women, but also includes other social identities (e.g., “strong” Black woman).

Settles (2006) also supported a unique integration of identities of woman and Black woman. Settles’ study of Black women’s perceptions of the importance of three identities –

woman, Black person, and Black women revealed that an intersection of identities as a Black woman was more important than the separate Black identity or woman identity. These findings supported an argument that the impact of the hemodialysis regimen on one's sense of "who I am as a woman" could be greater for African American women. Though a similar study was not found regarding African American men and their perceptions of their identities as man, Black person, and Black man, an examination of cultural influences on the Black male's construction of sexuality also should be considered.

Diminished Physical Sexuality Represents More Than Physical Sex

A persistent focus on sexuality expressed solely in the context of physical sex acts has contributed substantially to the belief that sexuality is a taboo subject. Maintaining this limited focus is further suggested to diminish meanings associated with being a man or woman. Findings from this study supported that an individual's perception of sexuality is an interrelated physical and psychosocial human life force versus only as a physical sex act. This finding is suggested to facilitate interventions that promote improved communication and assessment relevant to effectively addressing sexuality concerns by African Americans who are experiencing dialysis.

Sexuality concerns reported by participants involved more than their personal altered physical sexuality or sexuality identity. Instead, partnered male participants related that sexuality concerns affected their intimate partner relationships and created other household problems. The partners of these participants were reported to be excluded from access to information pertaining to their sexuality-related problems. The overall emphasis was that "the sexuality thing" tears up the home. This finding supported Valdez's (2000) statement that kidney failure was seldom an isolated illness. Similar to the patients, their partners (e.g., spouses or significant others) also had to make many adjustments in their efforts to maintain their intimate relationships. Participants in this study adamantly suggested that health professionals should help "fix the sexuality thing."

Additionally, suggestions were made for health professionals to include partners in discussions of sexuality-related issues in face-to-face communication and/or by written handouts.

A rationale for males who avoided discussing altered sexuality concerns was expressed by one participant. This participant declared that talking about sexuality problems makes “*you feel less than a person.*” Feeling less than a man when talking about sexuality implies the influence of an endorsement of normative or traditional male roles. Conversely, the same participant emphasized the “mental” strain of not being able to discuss or manage altered sexuality problems. This mental strain is suggested to hamper effective coping processes and adaptive behaviors. These findings supported the perspective that individuals with sexuality concerns both want and need to express their concerns. Participants emphasized that health professionals need to avoid viewing sexuality concerns solely as a “*medical problem.*” Additionally, an inadvertent endorsement of traditional masculinity can be promoted by health professionals who ignore perspectives of male (or female) identity outside of physical body functions. Such attitudes by health professionals may be perceived as supporting the view that physical sexuality is a more important element of being “all man” (or “all woman”).

Three men in this study suggested that they would be more willing to respond to sexuality related discussions with health professionals if these discussions were initiated by these professionals. However, other male participants reported that the dialysis center staff was rarely open to discussing sexuality issues beyond their physical bodily functions. Findings from the present study supported that an awareness of both patients needs and staff indifference was important for promoting effective communication between staff and patients. Effective communication between African Americans experiencing dialysis and health professionals caring for them is suggested to enhance the promotion of their individual’s experiences of satisfaction with their sexuality identity.

Unlike male participants in this study, female participants reported that their diminished physical sexuality state was primarily associated with decreased energy, age, and current stage of life. They reported fear of being a burden to their partners and concern with not having the right partner. Other women living with chronic illnesses have also indicated higher levels of sexual dysfunction. Among this group are women with multiple sclerosis (MS) who despite diminished physical sexuality, have described sexuality as important to their identity as a human (Gagliardi, 2002). Similar to women with MS, women experiencing dialysis were found to view factors associated with altered physical sexuality as threats to their personal sexuality identity, family-social roles as women, and intimate/personal relationships. This more holistic view of sexuality further supports the assertion that altered sexuality for men and women is broader than mere physical changes. Health professionals need to acknowledge and assess concerns related to altered physical sexuality for women receiving dialysis. Additionally, health professionals must be aware that this loss may represent a loss of “who I am as a woman” beyond the report of diminished physical sexual desire or ability.

Hemodialysis Regimen is an Emotional Rollercoaster

Participants in this study described intense and persistent negative emotions associated with the hemodialysis regimen. These intense emotions included: “hate,” feeling “as if on death row”, and “fear.” These negative emotions, along with the long physical hours attached to a hemodialysis machine, resulted in feelings of helplessness and perceived lack of control. Previous studies supported the idea that individuals on dialysis experience multiple negative emotions (Cinar, Barlas, & Alpar, 2009; Fowler & Baas, 2006). However, previous studies did not relate these negative emotions to individual perceptions of altered personal sexuality identity, family-social roles, and intimate/personal relationships.

Negative emotions associated with the hemodialysis regimen often are internalized and potentially can affect patients' individual sexuality. Rouse-Arnet, Dilworth, & Stephens, 2005 suggested that persistent negative messages and experiences could influence the Black woman's sense of sexual self. Responses from both female and male participants of this study indicated that persistent negative messages associated with the hemodialysis regimen could result in a loss of sensual self. Furthermore, the loss of sensual self is suggested to affect the individual's overall quality of life negatively. Findings from the present study supported a greater need to assess sexuality holistically in the context of various environmental stimuli (i.e., hemodialysis regimen) to which the individual is most frequently subjected.

Dialysis was acknowledged to be a positive "lifeline" by all participants. However, this lifeline was also noted as something that had to be endured versus having a positive acceptance of dialysis as a lifeline. This conflict is suggested to amplify perceptions of loss of personal control associated with the challenges of the dialysis regimen. Perceptions of loss of personal control are suggested to diminish perceptions of sexuality. Participants in this study reported decisions such as missing a day of hemodialysis treatment as justified behaviors for regaining perceived loss of control. For these reasons, health professionals need to be cognizant of seemingly nonadherence issues and their possible relationship to perceived altered sexuality concerns.

Participants in this study suggested that health professionals are also perceived as contributing to negative stimuli within the dialysis centers. Some reports described health professionals as being unconcerned about the personal lives of their dialysis patients, unwilling to provide privacy to discuss patient's sexuality concerns, and exhibiting insensitive attitudes. Previous research indicated that patients in hemodialysis centers perceived low levels of openness and sensitivity between staff and patients (Vitri, Attias, Bansyahu, Elharrat, & Hener,

2001). The staff's indifference was suggested to have been related to maintenance of a "psychological distance for self protection" (p.179). The following comment summarized participants' feelings: "*They just don't care . . . you know, it'll break you down.*" The majority of participants indicated that their African American identity was not associated with their perceptions of negative dialysis centers and staff. Furthermore, none of the participants suggested that their African American identity was associated with perceptions of the altering effects of the hemodialysis regimen on their sense of "who I am as men or women." The intensity of physical and emotional stressors associated with the unrelenting nature of the hemodialysis experience appeared to outweigh any influence of cultural differences.

Only People Experiencing Dialysis Understand

Participants admitted to frequently sharing hemodialysis associated concerns with dialysis patients having similar experiences despite a report of not having formal support groups in their dialysis centers. An interesting finding was that more women participants reported greater emotional and informational support from other individuals experiencing dialysis in comparison to male participants. This finding was consistent with Cameron and Lalonde's (2001) observations that women have a higher value of in-group support systems. Furthermore, Cameron and Lalonde argued that in-group support systems motivated individuals to maintain a positive personal and social identity.

The degree to which individual males endorse traditional masculinity ideology is suggested to influence the level in which relationships are established among men in dialysis centers. Evidence of this influence was supported by one male participant who related talking to other patients at the centers, but asserted that he never invited them to his home. Additionally, another male participant expressed being opposed to attending a support group within his

dialysis center due to concerns that these sessions would only become conduits of “negative venting” by individuals on dialysis.

Finding of less in-group support among men in the dialysis centers further supported Vitri, Attias, Bansyahu, Elharrat, and Hener’s (2001) finding that patients perceived little openness and sensitivity with other patients and staff in dialysis units. Vitri and colleagues suggested that the patients’ perceptions of less openness and sensitivity to others within dialysis centers might be related to perceptions of relationships as “temporary” or restricted to the time spent together at the center. Possible differences in the influence of perceptions of “temporary” relationships versus the valuing of in-group support systems should be further explored.

Despite a general defense of in-group support systems, the participants of this study reported few official support systems in their dialysis centers. A previous study supported the benefits of mutual support groups within dialysis centers (Chen, Pai, & Li, 2008). Chen and colleagues assessed participants’ needs prior to conducting support groups that were based on an empowerment concept. Fifteen patients in a Chinese dialysis center were included in eight bi-weekly mutual support group sessions. A nurse and social worker team facilitated the sessions which resulted in reports of decreased physical symptoms (i.e., itchy skin, insomnia, and muscular spasms); increased social networks; and improvement in quality of life scores related to emotional and health dimensions. The empowerment enhancing group work was suggested to “help patients re-gain their self-confidence, self-esteem, and self-identity” (p. 139). No similar studies of patients’ endorsement of mutual support groups within dialysis centers or with an African American population could be found.

Application of Sexuality Adaptation Model (SAM) as a Guiding Framework

The SAM was found to be an effective guide for the interview process and data collection for this study (see Figure 1, p. 19). The SAM was also found to guide the analysis of

participants' perceptions and adaptive responses relevant to sexuality concerns since being on hemodialysis effectively. Additionally, the study findings appear to support the theoretical assumptions of the SAM which included:

1. Sexuality is an element of overall well-being.
2. Sexuality is influenced by contextual biologic, psychological, social, and experiential factors.
3. Sexuality is an affirmation of life that is associated with one's connection or closeness with others.
4. Sexuality (e.g., vitality, physical attractiveness, social interactions, etc.) may be disrupted by chronic illnesses or treatments – thus promoting distance in relationships.

The primary concepts of the SAM include focal, contextual, and residual stimuli and sexuality coping processes, along with four adaptive modes that focus on a holistic view of sexuality behaviors. These concepts are defined similarly to concepts in Roy's Adaptive Model from which the SAM was derived (Roy, 2009; Roy & Anderson, 1999). The following paragraphs present a review of these concepts and their application to the findings of this study.

Stimuli. The theoretical concept, *sexuality state*, was used in the SAM to refer to hemodialysis associated focal stimuli (i.e., stressors) that influence an individual's perceptions of their sexuality. Focal stimuli are internal or external stimuli that confront an individual immediately, with contextual stimuli (e.g., demographic characteristics) contributing to influence of focal stimuli (e.g., stress of dialysis). Residual stimuli are stimuli that has undetermined or unclear effects on one's behavior. Findings of the present study revealed a complex set of hemodialysis associated stressors that were associated with participants' perceptions of sexuality. These focal stimuli included diminished physical sexuality; loss of time, energy and

independence; and altered family, social and work roles. The demographic data (e.g., length of years on dialysis) contextual stimuli) generally were not major contributing factors to perceptions of sexuality. Residual stimuli were noted to be potentially persuasive contributors to perceptions of sexuality. The endorsement of traditional masculinity ideology was identified in this study as a residual stimulus that notably influenced male participants' perceptions of physical sexuality, personal sexuality identity, family-social roles, and intimate relationships.

Sexuality coping processes. *Sexuality coping processes* are an aspect of the cognator subsystem and are represented by four emotive channels defined by Roy as perception and information processing, learning, judgment, and emotion (Roy, 2009; Roy & Andrews, 1999). Roy indicated that individuals' perceptions or conscious appreciation of stimuli often determine their adaptive reactions to the stimuli. Findings of this study showed that an individual's perceptions of a specific stimulus (e.g., diminished physical sexuality) and its contributing factors (e.g., lack of relationship) either increase or minimize effects of specific stimulus. This emotive channel was illustrated by one participant's report of feeling "less than a man" when confronted by his diminished physical sexuality. A particularly strong endorsement of traditional masculinity that included high expectations of sexual performance was revealed as a contributing (residual) stimulus to this individual's state of diminished physical sexuality. This participant's resulting behaviors reflected a greater diminished sense of "who I am as a man" than was suggested by other men in response to similar stimuli.

Sexuality adaptation modes. The interconnectedness of adaptive modes (behaviors) associated with physical sexuality, personal sexuality identity, family-social roles as men or women, and personal/intimate relationships were indicated by the findings of this study. The support of sexuality as a holistic concept was demonstrated in the five themes that emerged from participants' descriptions of their sexuality. For example, 10 of the 19 participants admitted to a

diminished physical sexuality state, but identified their supportive roles (e.g., parent, partner, etc.) and accomplishments (e.g., providers and caregivers) as equally or more relevant to their perceptions of sexuality as elaborated by one participant: “Just because I’m on dialysis, that don’t mean that my wife, my daughter, my son, my grandbabies don’t still depend on me.”

Strengths and Limitations of the Study

This study’s strength included the utilization of a guiding framework that was derived from a well established nursing theory (Roy’s adaptation model). The middle-range theory (SAM) assisted in maintaining focus on the specific aim of the research. The rich data from both male and female study participants with varied demographics provided a major strength to the study. An additional strength was application of rigorous qualitative research methods that guided data collection (i.e., use of a theoretically based semi-structured interview guide) and analysis of the data (i.e., review of transcripts coding by other health professionals [e.g., the investigator’s nursing faculty advisor, two African American nurses experienced in the study of sexuality and currently enrolled in doctoral study programs, and an attending nephrologist with experience working in urban center dialysis units]).

A limitation of this study, and many qualitative studies, is the generalizability of the findings. The sample was limited primarily to middle-aged African American men and women from two urban dialysis centers in the metropolitan Detroit area. Findings therefore are not generalizable to all individuals who experience dialysis or are dialyzed in other settings. In addition, single interview sessions with participants limit the depth of understanding possible to obtain with a complex topic such as human sexuality. Variations and differences in perceptions of sexuality related to contextual stimuli (e.g., strong partner support) and residual stimuli (e.g., personal beliefs and values) are important variables that were not entirely reflected in a single interview session. In retrospect, a focus on fewer concepts and longer interviews would have

helped to obtain more information and expand the depths of understanding. For example, interview questions did not intimately explore the effect of the expressed negative emotions on the individual's sense of "who I am" as a woman or man. Further study is needed in this area. As with most qualitative studies, the inability to validate information from personal interviews adequately was an additional limitation of this study.

Implications for Clinical Practice and Future Research

Nurses and other health professionals need to assess and promote positive expressions of sexuality among African American patients who are experiencing dialysis. Health professionals need to be aware of their attitudes and roles manifested within dialysis center settings that promote perceptions of diminished sexuality among their patients'. These professionals also need to understand the effects that chronic illnesses and treatments, such as hemodialysis, have on an individual's perceptions of their sexuality. Additionally, differences in male versus female perceptions of support systems within dialysis centers should be explored further.

Health professionals need to be aware of cultural factors and individual belief systems that influence perceptions of sexuality. Further exploration of staff attitudes and specific hemodialysis associated stressors that promote perceptions of diminished sexuality is also recommended. Additionally, the benefit of mutual support groups and the differences in male versus female perceptions of support systems within dialysis centers should be further explored.

Real-life experiences related to sexuality concerns are not captured by a limited focus on the number of men struggling with erectile dysfunction. Research recommendations include the development of a holistic sexuality survey tool that incorporates items from the interviews to facilitate quantitative study of a larger group of people and in-depth exploration of sub concepts of sexuality (i.e., physical sexuality, personal sexuality identity, family-social roles as men or women, and intimate/personal relationships). Further exploration of cultural factors and

individual belief systems that influence perceptions of sexuality among patients experiencing dialysis is also recommended. An intensive study of a larger group of men and 'or women could help to better understand the gender differences found in this study: particularly the differences in gender ideology among African American participants undergoing hemodialysis. Promotion of patients' expressions of "satisfaction with sexuality" must include appropriate methods to encourage discussions of both physiological and psychological concerns associated with sexuality. The inclusion of partners and their concerns need to be recognized as an essential element of interventions developed for dialysis patients (e.g., professionalism of dialysis center staff in urban areas and among low-socioeconomic groups). In addition, further evaluation of theoretical frameworks that promote increased knowledge and comfort with discussions of physiological and psychological sexuality concerns for health professionals and patients alike is needed. These frameworks should consider cultural differences, health problems, and health care environments of specific populations

Conclusions

With the lack of literature on the experiences and perceptions of sexuality among African American participants on dialysis, this study provides a beginning foundation for better understanding factors that influence perceptions of the effects of the hemodialysis regimen on sexuality. Findings support the assertion that a holistic approach is needed to adequately assess perceptions of sexuality and to guide related research and clinical interventions. The utilization of holistic frameworks to assess sexuality is suggested to aid greater understanding and acceptance of the individual on hemodialysis as a whole person. Kralik, Koch, and Telford (2001) suggested that such acceptance encourages these individuals to ask questions and seek assistance with their sexuality issues. Nurses and other health professionals need to understand that sexuality encompasses the total person. One study participant stated that hemodialysis

dialysis regimens “*tear up relationships*”. A diminished sense of self can minimize effective coping processes and adaptive responses. As was so eloquently stated by one participant, health professionals have a responsibility “*to fix this thing.*”

Consistent with guidelines by the American Nephrology Nursing Association (Burrows-Hudson & Prowant, 2005) and the American Nurses Association (2004), this study also illuminated the importance of identifying effective strategies for assessing patients’ expressions of satisfaction with sexuality as a holistic concept. Additionally, an informed awareness of patients experiencing dialysis and their partners’ perceptions of their sexuality is necessary to develop adequate assessment and supportive interventions for these patients. Furthermore, the perception of improved care is the patient’s expressions of satisfaction with their care which also fosters positive adaptation.

APPENDIX A

Human Investigation Committee

Approval



HUMAN INVESTIGATION COMMITTEE
101 East Alexandrine Building
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
<http://hic.wayne.edu>



NOTICE OF EXPEDITED APPROVAL

To: Merry Stewart
College of Nursing
2220 AAB

From: Ellen Barton, Ph.D. E. Barton
Chairperson, Behavioral Institutional Review Board (B3)

Date: May 23, 2008

RE: HIC #: 056208B3E
Protocol Title: Perceptions of Sexuality by African American Patients on Hemodialysis
Sponsor: AMERICAN NEPHROLOGY NURSES ASSOCIATION
Coeus #: 0805006018

Expiration Date: May 22, 2009

Risk Level/Category: No greater than minimal risk.

The above-referenced protocol and items listed below (if applicable) were **APPROVED** following *Expedited Review* (Category 7*) by the Chairperson/designee for the Wayne State University Behavioral Institutional Review Board (B3) for the period of 05/23/2008 through 05/22/2009. This approval does not replace any departmental or other approvals that may be required.

- Recruitment Letter
- Information Sheet

- Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval **before** the expiration date. Data collected during a period of lapsed approval is unapproved research and can **never** be reported or published as research data.
- All changes or amendments to the above-referenced protocol require review and approval by the HIC **BEFORE** implementation.
- Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the HIC Policy (<http://www.hic.wayne.edu/hicpol.html>).

NOTE:

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the HIC office must be contacted immediately.
2. Forms should be downloaded from the HIC website at each use.

*Based on the Expedited Review List, revised November 1998

APPENDIX B

Human Investigation Committee Approval Continuation

**WAYNE STATE
UNIVERSITY**

HUMAN INVESTIGATION COMMITTEE
101 East Alexandrine Building
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
<http://hic.wayne.edu>

**NOTICE OF EXPEDITED CONTINUATION APPROVAL**

To: Merry Stewart
College of Nursing
2220 AAB

From: Ellen Barton, Ph.D. _____
Chairperson, Behavioral Institutional Review Board (B3)

Date: May 14, 2009

RE: HIC #: 056208B3E
Protocol Title: Perceptions of Sexuality by African American Patients on Hemodialysis
Sponsor: • AMERICAN NEPHROLOGY NURSES ASSOCIATION
Protocol #: 0805006018

Expiration Date: May 13, 2010

Risk Level/Category: 45 CFR 46.404 - Research not involving greater than minimal risk

Continuation for the above-referenced protocol and items listed below (if applicable) were APPROVED following Expedited Review by the Chairperson/designee of the Wayne State University Institutional Review Board (B3) for the period of 05/14/2009 through **05/13/2010**. This approval does not replace any departmental or other approvals that may be required.

- Recruitment Letter
- Information Sheet

- Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval **before** the expiration date. Data collected during a period of lapsed approval is unapproved research and can **never** be reported or published as research data.
- All changes or amendments to the above-referenced protocol require review and approval by the HIC **BEFORE** implementation.
- Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the HIC Policy (<http://www.hic.wayne.edu/hicpol.html>).

NOTE:

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the HIC office must be contacted immediately.
2. Forms should be downloaded from the HIC website at **each** use.

*Based on the Expedited Review List, revised November 1998

APPENDIX C

Nephrology Letter of Support



Department of Internal Medicine
Division of Nephrology
4160 John R., Suite 908
Detroit, MI 48201

April 25, 2008

Stephen D. Migdal, MD, FACP
Division Chief

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Nephrology Clinics Suite 917
Appointment # (313) 745-4525
FAX# (313) 745-0011

Re: Dissertation Proposal of Merry A. Stewart, RN

To Whom it May Concern:

This letter is in support of recruitment for Ms. Stewart's research project "Perceptions of Sexuality in African-American Dialysis Patients".

I have reviewed Ms. Stewart's research proposal and concur with the clinical relevance of the work. I am the attending physician on a large number of dialysis patients, and I agree to discuss this project with potentially eligible candidates for the purpose of recruitment, subject to WSU HIC approval and regulations.

A handwritten signature in blue ink, appearing to read "James Sondheimer", is written over the typed name.

James Sondheimer, MD, FACP
Associate Prof. Medicine
Wayne State University School of Medicine
Medical Director, Hemodialysis Unit Harper
University Hospital
Medical Director, DaVita Greenview Dialysis

APPENDIX D

Recruitment Letter

Effect of Dialysis Routine on Male and Female Identity

Dear _____ (Patient)

My name is Merry Stewart. I am an African American nurse practitioner and a doctoral nursing student at Wayne State University. I want to talk to African Americans about the ways that the hemodialysis routine affects your identity and roles as a man or woman.

Sexuality concerns can be common for dialysis patients, but little is known about the effect of dialysis on the patient's overall sexuality – **that is the effect of dialysis on your identity and roles as a man or woman.** The information from this study may help health professionals to better understand and interact with dialysis patients regarding the effect of dialysis on sexuality issues.

To participate in this study, you must be African American, between 20 to 60 years of age, and have been on hemodialysis for at least 3 months.

A Gift of \$30.00 will be given to compensate for your time involved in completing the study.

Interviews for this study can take place in your home or another location of your choice. I will conduct all interviews. **If you are interested in this study, please complete the form below and return it in the addressed pre-stamped envelope.** I will contact you by phone and give more information about the study. I will also set a time for a meeting to discuss the study, get your consent for the study, and complete an interview with you. If you have questions about this



study, you can call Merry Stewart at: **313 303 1083.**

_____ **I am interested in participating in this study about the effect of the hemodialysis routine on my identity and roles as a man or woman. My name is _____.** I may be contacted at this phone # _____. The best time to reach me is _____. I prefer to meet (check one): in my home _____ at another location _____.

APPENDIX E**MacNeill-Lichtenberg Decision Tree****A. Cognitive Indicators: Benton temporal Orientation Test**

	RESPONSE	CORRECT	ERROR SCORE	
WHAT YEAR IS IT?	_____	_____	_____	10 PTS OFF/YR MAX = 60.
FULL CREDIT IF WITHIN 15 DAYS				
WHAT MONTH IS IT?	_____	_____	_____	5 PT OFF PER MONTH, MAX = 30.
WHAT IS THE DATE?	_____	_____	_____	1 PT OFF PER DAY, MAX = 15
DAY OF THE WEEK?	_____	_____	_____	1 PT OFF PER DAY, MAX = 3
WHAT TIME IS IT?	_____	_____	_____	1 PT OFF PER ½ HR MAX = 5
TOTAL ERROR POINTS				_____

COGNITIVE INDICATORS: Animal Naming

"TELL ME AS MANY ANIMALS AS YOU CAN THINK OF: YOU HAVE ONE MINUTE" (Time 60 sec, Score = number of different animals)

- | | | | |
|---------|---------|----------|----------|
| 1 _____ | 5 _____ | 9 _____ | 13 _____ |
| 2 _____ | 6 _____ | 10 _____ | 14 _____ |
| 3 _____ | 7 _____ | 11 _____ | 15 _____ |
| 4 _____ | 8 _____ | 12 _____ | 16 _____ |

TOTAL _____

IF ORIENTATION ERRORS ARE GREATER THAN 3 OR ANIMAL NAMING IS LESS THAN 10 REFER TO PSYCHOSOCIAL INDICATORS BELOW.

B. PSYCHOCOSICAL INDICATORS

DOES THE PATIENT LIVE ALONE?	<u>YES/NO</u>
DOES THE PATIENT COMPLETE ALDS/ALDS UNSUPERVISED?	<u>YES/NO</u>
IS THE FAMILY AWARE OF COGNITIVE DEFICITS?	<u>YES/NO</u>

IF ANY ONE IS ANSWERED IN THE INDICATED FASHION →

REFER TO NEUROPSYCHOLOGY OR COGNITIVE EVALUATION

C. EMOTIONAL FACTORS

1. DO YOU FEEL THAT YOUR LIFE IS EMPTY?	<u>YES/NO</u>
2. DO YOU OFTEN FEEL DOWN HEARTED AND BLUE?	<u>YES/NO</u>
3. DO YOU FEEL PRETTY WORTHLESS THE WAY YOU ARE NOW?	<u>YES/NO</u>

IF PATIENTS ANSWERS YES TO JUST 1 OF THESE →

REFER TO NEUROPSYCHOLOGY FOR EVALUATION OF DEPRESSION

APPENDIX F

Demographic, Medical History and Sexuality Relationship Questionnaire

Demographic/ Medical History/Sexuality Relationship Survey

Age ____years Birth date _____ (month, day, year)

Gender ____Male ____Female Where were you born? _____

Marital or Relationship Status: (please check all that apply)

Single ____ Living with Partner ____

Widowed ____ Divorced ____

Married____

Not in Current Steady Relationship____ Length of time Married, with Partner or Steady

Currently in Steady Relationship____
Relationship _____

Do you have children ____ yes ____no; living with you or in metro Detroit ____ yes ____no

Level of Completed Education:

Less than high school____ Some college____

High school diploma/GED____ College degree____

Employed: Yes __ No __ Type of work you do/did: _____**Age: 1st dialysis treatment ____ Years/months since on hemodialysis ____ months**
____ years**Medical History (Please check if you have current diagnosis or treatment of any of the following):**

Diabetes____ Menopause____ Heart Disease____

Hypertension____ Depression____ Other_____

Multiple Sclerosis____ Psychiatric Illness____

Paralysis____ Currently Pregnant____

List all Medications:**Sexual History: (Please check yes or no to the following):**

Are you currently sexually active? ____yes ____no When was the last time you had sex? _____

APPENDIX G**Sexuality Interview Guide**

A common problem stated by many hemodialysis patients is that of concerns related to the effect of hemodialysis on sexuality or on one's identity as a male or female. I am going to ask you to describe your thoughts and feelings about the effect of hemodialysis on physical changes, your personal identity, roles and relationships as a man/woman. Information related to concerns or changes as a man or woman since being on dialysis is important to recognizing or understanding sexuality concerns and their possible effects on the management of your dialysis routine.

1. First of all, think about the phrase – He/She is all man/woman. Describe in your opinion that man/woman?

a. Probes

- i. Body image/appearance; self-image (personal and physical sexuality modes)**
- ii. Other physical changes (e.g. sexual functioning, urination patterns, etc.) (physical sexuality mode)**
- iii. Family – social roles (family-social role mode)**
- iv. Intimate relationships (intimate/personal relationship mode)**

2. How would you describe you as a man/woman?

a. Probes

- i. Body image/appearance; self-image (personal and physical sexuality modes)**
- ii. Other physical changes (e.g. sexual functioning, urination patterns, etc.) (physical sexuality mode)**
- iii. Family – social roles (family-social role mode)**

iv. Intimate relationships (intimate/personal relationship mode)**Sexuality Interview Guide (continued)****3. Describe how hemodialysis and the routine associated with dialysis affected you as a man/woman?****a. Probes**

- i. Body image/appearance; self-image (personal and physical sexuality modes)**
- ii. Other physical changes (e.g. sexual functioning, urination patterns, etc.) (physical sexuality mode)**
- iii. Family – social roles (family-social role mode)**
- iv. Intimate relationships (intimate/personal relationship mode)**

4. How would you compare yourself to other men/women who are on dialysis?**A. Probes**

- Body image/appearance; self-image (personal and physical sexuality modes)**
- Other physical changes (e.g. sexual functioning, urination patterns, etc.) (physical sexuality mode)**
- Family – social roles (family-social role mode)**
- Intimate relationships (intimate/personal relationship mode)**

Sexuality Interview Guide (continued)**5. How would you compare yourself now to other men/women who are not on dialysis?**

- a. **Probes**
 - i. **Body image/appearance; self-image (personal and physical sexuality modes)**
 - ii. **Other physical changes (e.g. sexual functioning, urination patterns, etc.) (physical sexuality mode)**
 - iii. **Family – social roles (family-social role mode)**
 - iv. **Intimate relationships (intimate/personal relationship mode)**
6. **Do you think that any of the concerns that you have mentioned would be different if you were not African American?**
- A. **Probes**
 - **Body image/appearance; self-image (personal and physical sexuality modes)**
 - **Other physical changes (e.g. sexual functioning, urination patterns, etc.) (physical sexuality mode)**
 - **Family – social roles (family-social role mode)**
 - **Intimate relationships (intimate/personal relationship mode)**
7. **What else would you like health care providers to understand about the dialysis routine and how it affects physical functioning, your identity, relationship, and roles as a man/woman?**

APPENDIX H

Research Informed Consent

Title of Study: *Perception of Sexuality by African American Patients on Hemodialysis*

Principal Investigator (PI): Merry A. Stewart
College of Nursing
313 303-1083

Funding Source: American Nephrology of Nursing Association

Purpose:

You are being asked to participate in a research study of the effect of hemodialysis on your identity and roles as a man/woman. This research study is associated with the investigator's studies in the PhD (doctoral) program of Wayne State University College of Nursing. The number of estimated number of study participants to be enrolled is about 20. **Please read this form and ask any questions that you may have before agreeing to be in the study.**

In this research study, you will be asked to state your thoughts and feelings about the effect of hemodialysis on your sexuality. Sexuality includes your self-identity, changes in your roles as a family and community member, and intimate or personal relationship as a man/woman.

This study is being conducted by Merry Stewart, RN, MSN, APN. The investigator is an advanced practice nurse and a student in the PhD program of the College of Nursing at Wayne State University.

Study Procedures:

If you agree to participate in this research study, you will be interviewed by the investigator of this study, Merry Stewart. During this interview, you will be asked to complete a screening tool to evaluate your basic ability to participate in the study. You will also be asked personal information about your age, gender, marital status, and level of completed education, length of time since being on dialysis and basic medical and sexuality relationship history. Completion of this information is expected to be less than 10 minutes.

You will also be asked to respond to questions about your sexuality or about your identity and roles as a man/woman since being on dialysis. The interview will take place in a private setting. The sexuality interview will be audio taped in order to maintain the flow of conversation and for accurate record keeping. The sexuality interview is expected to take 60 minutes. You may choose not to answer any questions that make you feel uncomfortable.

Benefits

As a participant in this research study, there may be no direct benefits for you; however, information from this study may benefit other people now or in the future.

The possible benefit to you for taking part in this study is an increased awareness of sexuality that may be associated with dialysis. Information from this study may help your doctors, nurses, and other health care professionals to better communicate with dialysis patients in the future about sexuality changes and concerns related to dialysis.

Risks

By taking part in this study, you may experience feelings of discomfort related to the questions that are asked. You may choose not to answer any questions that make you feel uncomfortable.

Costs

There will not be any costs to you for participating in this study.

Compensation

A monetary gift of \$30.00 will be given to you following the interview to compensate for your time and any inconvenience related to this study.

Confidentiality

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Human Investigation Committee (HIC) at Wayne State University or federal agencies with appropriate regulatory oversight (e.g., Food and Drug Administration [FDA], Office for Human Research Protections [OHRP], Office of Civil Rights [OCR], etc.) may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity. If photographs, videos, or audiotape recordings of you will be used for research or educational purposes, your identity will be protected or disguised. The exact words of the audio tape(s) will be written on paper for further study by the investigator. All audio tapes and the written information will be kept in a locked file and only available for review by the investigator. All audio tapes and written information will be destroyed following review and listing of the main points of information. Only the main point so information may be included in the final report of this study.

Voluntary Participation /Withdrawal:

Taking part in this research study is voluntary. You have the right to choose to not take part in this study. If you decide to take part, you can later change your mind and withdraw from the study. You are free to not answer any questions that you do not choose to answer. You are free to withdraw from participation in this study at any time. Your decision will not change any present or future relationships with Wayne State University or its affiliates or other services you are entitled to receive.

The PI may stop your participation in the study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study.

Questions:

If you have questions now or in the future, you may contact Merry Stewart at the following phone number: 313 313-1083. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at 313 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

Participation:

By completing the questionnaires and interview, you are agreeing to take part in this study.

APPENDIX I

Post Interview Summary Form

1, Respondent Behavior

2. Interview time, interruptions or distractions

3. Primary themes or issues

4. Limited/guarded; strongly emotional or emphatic responses

5. New themes or suggested questions

6. Interviewer's responses/concerns

APPENDIX J**Glossary of Key Concepts in Roy's Adaptation Model (Roy, 2009) and Sexuality****Adaptation Model**

Adaptation: The utilization of conscious awareness and choice by humans to create integration with their environment.

Adaptation Level: A condition of life processes; may be either integrated (meets human needs), compensatory (coping processes are activated, but not fully meeting human needs), or compromised (inadequate integrated and compensatory process).

Adaptive Responses: Human behaviors that reflect reactions to specific stimuli. Roy identified four adaptive modes that reflect adaptive responses – physiologic, self-concept, role function, and interdependence.

Cognator Subsystem: Encompasses coping processes which reflects acquired processes of humans (i.e., perceptions and information processing, learning, judgment, and emotion). The cognator subsystem is a major theoretical component of the SAM.

Contextual Stimuli: Stimuli that contribute to the affects of directly confronting stimuli (e.g., age, gender, etc.).

Environment: All conditions, circumstances, and influences that surround and affect human development and behavior.

Family-Social Role Mode: Encompasses behaviors relevant to roles assumed in the family or community; is associated with the role function mode in RAM.

Focal stimuli: Environmental stimuli that most immediately confronts the human system.

Interdependence Mode: One of four adaptive modes that focuses on close relationships of humans.

Intimate /Personal/ Relationship Mode: Encompasses behaviors relevant to one on one intimate or personal relationship(s); is associated with interdependence mode in RAM.

Personal Sexuality Mode: Encompasses behaviors reflective of self-identity and body image as men or women; is associated with the self-concept mode in the RAM.

Physiologic Mode: One of four adaptive modes that includes physical and chemical processes.

Regulator subsystem: Encompasses coping processes that involve the neural, chemical, and endocrine systems.

Residual Stimulus: Stimuli that are not obvious, but able to influence an individual's sexuality state; can become focal stimuli (e.g., strong spiritual faith).

Role Function Mode: One of four adaptive modes that relates to roles of humans (e.g., the parent role).

Self-Concept Mode: One of four adaptive modes that relates to personal aspects of human systems.

Sexuality Coping Processes: Acquired processes by which humans interact and influence stimuli related to sexuality that pertain to the cognator subsystem in the SAM.

Sexuality State: Stimuli associated with the hemodialysis regimen and aspects of individual sexuality that directly confronts an individual.

Stimulus: An element that provokes human response(s).

APPENDIX K

Sample Transcript – Participant S (identifiers removed)

- PI: A common problem stated by many hemodialysis patients is that of concerns related to the affect of the dialysis regimen on their identity as a male or a female. I'm gonna ask you about thoughts and your feelings about the affect of dialysis on your identity and roles as a man. Information related to your thoughts and feelings about the affect of dialysis on your identity and roles is important to recognizing or understanding any sexuality concerns and their possible affects on the management of your dialysis routine. Now first of all, often, one hears the phrase or may hear the phrase, "He's all man". Describe, in your opinion, that man.
- S: *A man that's strong, that's able to, uh, take care of his family, get up and do, uh, physical things about the home, um, and someone who'll protect and be a viable person towards his family – that's physically, mentally, and financially if possible.*
- PI: How does that man look or dress; any certain way – that "all man"?
- S: *No, he can be a white collar worker, blue collar worker. You know, it's just someone that's – look like they just physically strong and able to take care of the home, the family, and be viable and do, uh, activities with the family, you know, play with the kids.*
- PI: Okay.
- S: *Which, you know, that's not a lot of things that's going on now with a lot of men, you know. They don't play with the kids like they used to. They don't spend the time with the family. It's all about them.*
- PI: How would you describe you as a man?
- S: *I think I'm up to the part to a certain extent. What I mean by that is the days I do go to dialysis I just don't feel like I'm that particular person because I be drained. I can't get up and play with my son. He want to play basketball, throw the ball around. I'm not able to do that because I be too tired, and, um, but the days I'm not where my strength do sometime come back, them the days I – you know, that's Monday – Tuesday, Thursdays and Saturdays and Sundays where I will be able to get up, play with him. You know, me and him go out there, cut the grass, you know, wash the car, the truck, you know, play baseball, throw the football around, you know, ride the bikes up and down the street when we can, you know. But it's days he – Monday and Wednesday and Fridays he want to do it, I can't do it, and he be like, "Why?", but he really don't understand because he six.*
- PI: Oh, okay. Can you expand more on how dialysis and the routine affected with dialysis affects you as a man?

S: *Oh. Well it still affects me more than that because I used to love fishing and sometime I be so weak where it's like my...how can I explain it, that I be too weak to be really confident to be by the water.*

PI: Okay.

S: *So if I'm feeling like that I don't go because I don't know what might happen and I'm not strong enough to take care of myself to do that. I don't want to be out there like that. You know, and then my son likes to go with me so that's another thing. I would have to watch him, too, you know, and then I used to love lifting weights. I used to love bowling. I can't really get into that no more because, you know, you got to run and my back messed up now and the dialysis is, uh, it just limit me to a lot of things I used to do, and I really don't like it.*

PI: I've heard people also talk about travel, for instance out of town or certain vacations, certain family plans.

S: *That's – that – yeah, the family planning is really not too bad of a issue. I just don't like because when we take a road trip, we drive so it really don't bother me as bad, but it's just that when you wanna – when you take a vacation, you want to take a vacation. You don't want to have to stop, go get treatment for three, four hours and then have to – but then because you be too tired to do anything. So it's not really a vacation.*

PI: Hmmm, okay.

S: *You know, it's basically you still being into the same program like you was at home. You're going to dialysis, still being drained. You're not getting – you're not being really active to doing the stuff you want to do, which if you're on a vacation and everybody out playing or enjoy themselves having fun, and you can't do it because you got to limit yourself.*

PI: Earlier, you said that the [physical sexual] urge was there initially within the first year of dialysis. Explain to me how that's changed and what do you think changed?

S: *Well the first year – well, I was still kind of sexually active. I mean I would still enjoy it three, four times a week where as time went on, within the first year – the first year I was okay with it. The second year, it kind of dropped some where it started getting lesser like two times a week. Um, now where it – where dialysis now, my peak of that, it – it's – oh, God, how can I explain it? It don't be there no more like it used to. I mean, I have it in my head, but it don't work down there.*

PI: Okay.

S: *That's the best way I can explain it, and so in order for me to have any kind of stimulation to want to actually do it down there is that I have to take Viagra or Valitra or something to actually make anything function.*

PI: Okay, so as you said you have it in your head – I would assume then that the desire of the relationship for closeness, is unchanged?

S: *Yeah, it's nothing changed. I would love – you know, I love my wife and I love to be with her, but when that part of your body don't work functionally right, I mean, you got to think of other ways to do it.*

PI: Can you tell me some of those other ways?

S: *Um, the other ways is like I say, you got medication. I mean, you know, sexual medication, um, sometime role plays, use toys, however, you know – because I don't want. You know, I hear about a lot of people relationships go totally downhill after they get on dialysis. I know a lot of people that – their relationships – they be married and when they get on dialysis and that first two years, they divorced or separated because due to the fact that a lot of men – well, I don't know about the women, but a lot of men, they sexual desires goes away because of them being on dialysis, and I don't understand – I guess because the filtering. I don't know what it is, or the medication, but the sexual desire goes away where when they used to have sex – like me I still like to – love women and, you know, I still would love to have sex what – four to five times a week of I could, but I just can't.*

I: Is that anything that you've ever talked to the health care, social care staff about; and have you thought of other ways to provide a closeness to your relationship - holding hands, as you said role play, that other things can also be a part of the relationship and not just the physical part.

S: Right, uh, well you know, we do all that. I mean we hold hands, you know, we cuddle. We do – well I try to do anything to keep the...

PI: Romance.

S: *Yeah, the romance involved in our life. You know I don't just – I'm not going to do this now. I mean, my wife and my kids is my life and whatever I have to do to keep my life together, I'm gonna try, no matter what it is and I mean I've talked to social workers, because at first, um, the government did used to allow you 10 Viagra pills in a month. They used to. I tried getting them before. They don't do it anymore, but when I was getting them, the 10 always helped because they \$20.00 apiece, and when your money is limited, that they – I have to keep lights on instead of paying for that. So that's when I have to do other things to keep the romance involved in our life.*

PI: Have the social workers or the doctors or nurses, do they ever initiate this conversation themselves?

S: *Well they did the first year, but I guess after the first year I guess they figure if you got any problems or anything that you will come to them, I guess.*

PI: Do you think that's true – most people would come to them?

- S: *Yeah, but they won't because a lot of people don't want to talk about it.*
- PI: Okay. So if the providers initiated it continuously, you know, according to certain – say a yearly kind of exam or physical or whatever. Do you think that would be appropriate or that should happen?
- S: *I think it would be appropriate, especially for a person on dialysis because sometimes people – they – I really wouldn't talk about it because you feel less than a person when you talk about it, you know. You feel like you're not that particular man because things is going wrong with you, which – that's not to your fault, but now you sick where things is happening to you and you never was expecting to have happen to you because I never thought I would be – because I always worked from the age was 16.*
- PI: Okay.
- S: *I never was without a job. I always had a job, and when this happened to me and now everything is limited, I still feel funny not doing a lot of work I used to do, because I'm used to getting up at 5:00 in the morning working all day – not just sitting around the house not doing nothing.*
- PI: What were you employed as before?
- S: *I was employed with the City Parks and Recreation. I used to do landscaping, cut trees down, do concrete work, put fences up for the city. I used to do the landscaping where I had the flower beds. You know, I mean I had multiple tasks and duties. So my job wasn't just limited.*
- PI: How long have you not been working now?
- S: *Since 2000 – no '99; got sick in '99. I went on dialysis in 2000.*
- PI: Okay. Going back to what you said that it's often difficult for people to talk about – for men at least– to talk about their sexuality if they're feeling less than a man. If it was brought up again in an annual, say, kind of manner, twice a year format, should that happen? Would that make one comfortable in talking about it if someone else initiates it?
- S: *I mean it – I think to my knowledge it would because – especially if you got a – if you like do it in private, not at like into the dialysis unit where you got people sitting. You know what I'm saying? Because people would like they little stuff to be private because people don't like to talk about that, you know, especially when it's dealing with you and the function of your body, your sexual life, because a lot of people want that part of their life private. They don't want to talk about that, which I could understand that. I wouldn't want to talk about it.*
- PI: Right. How often do you meet in private with either the nurses or the social worker or the doctor?

S: *The social worker, I meet privately maybe – she got a office so that's good because she's right there in the dialysis unit. Um, the doctors, the only way you meet with them in private if you go out to they office, and there you don't meet them. They come right to your bed and they talk to you if you need any medication. They look at your chart, look at blood work, what has been done on you and they try to adjust your meds and everything there, which that's not a problem. I don't care about that, but you know, they won't bring up about your sexuality because like when I got the medication I was starting to get, when I asked for a, um, the Viagra and stuff, I pulled them to side because I didn't want to talk in front of everybody.*

PI: So usually it's very limited that you're at their office, unless there's some medical problem that you had to go for.

S: *Right.*

PI: But mostly you see them all year and all the time while in that chair?

S: *Yeah, exactly.*

PI: I can understand how that would difficult. Another thing that individuals have spoken of in regards to their identity and how they feel it might affect them as a man or as a woman, is the body scars, the scarring. How does that affect you?

S: *Uh, the body scarring, it's – I don't like but, I mean, you got to live with it because of the situation, but it's – I see some doctors do neat work, put it that way, but then I see some doctors do bad work. You know, and it seem like if they gonna send someone to have those type of things, you know, things done to them while they on dialysis where they get they sites and stuff put in, they should have somebody that know how to do really good cosmetic surgery because I see it – I mean by me being on it so long, I done seen it all. I mean I done seen good work and I done seen bad work, and it, it really don't bother me because – especially when you do good work, because – and then you got some of the, some of the doctors that when they do do the work, they do try to, uh, they tell you – if they a good doctor. I can't say all doctors, but they tell you what to put on it to try to, to make your scars blend in.*

PI: Okay.

S: *You know to kind of, you know, make it heal, look better than what it actually supposed to look like, you know, and a lot of doctors don't. They just, okay, you just another number and another body to them, and the doctor that did me, Dr . . . , he was a good – because he told me what to put on my scars and my scars did good.*

PI: Okay, are you saying that yours don't really bother you?

S: *No.*

PI: Tell me, how would you compare yourself to other men who are on dialysis?

S: *I think I'm one of the better men that I can see that's been on dialysis for a long time because most of the men that I do see that's on dialysis now, and they ain't even been on it longer than me, they look like they be just out of it all the time. I don't understand why. I don't know if it's they eating habits is the way mine's is or they taking the medications the way the supposed to, but they just look like they so drained and can't do anything for themselves, and me, I, I do – I basically try to do everything I can. I'm not fin to try to limit myself.*

PI: Okay. Now you're – age wise I think you're the younger end. Is that correct for most of the men or would you say a lot of them are around...?

S: *No, I mean I – it's some there that's in a – in the upper-50's to me, but it's some that's younger than me there. Well at the clinic I'm at, I mean, uh, it's one guy there he's – I think he's 18 or 19.*

PI: Okay.

S: *But he be acting like he can't do anything.*

PI: Oh, okay.

XXX: *He be acting like he so drained and tired all the time. I don't know what his lifestyle is, but me, I try to do everything I can to keep me still healthy and active as I can.*

PI: Okay. What do you think gives you that positive attitude?

S: *My wife.*

PI: Okay.

S: *She push me to don't limit myself no matter what's wrong with me, and I think if you got a good strong family background and someone that's always in your corner to push you to try to do excellent work or do whatever you can to better yourself, that's a good thing, which a lot of people don't have that family support.*

PI: Okay, so that makes a huge difference – that support.

S: *Yeah, I mean you could have support out there in the community but it's nothing like when you're at home, I mean, because your family can bring you down. You know they always – some families say you ain't worth nothing because you this, this and that. You know what I'm saying? Because you on dialysis now, they think that the only thing you want to do is be dependent on them and it's really not that way, but if you got a strong family, you know, you can do this. You ain't got to sit there and not do nothing, you know, and they steady pushing you. It's basically – to me it's basically like how your grandmother and your mother raised you from back in the day.*

PI: Okay, okay.

S: *Because if you didn't have that strong family background then, um, you probably wouldn't be – you probably would depend on everybody else.*

PI: Okay. Where were you born and raised as a child?

S: *I was born and raised here.*

PI: Okay. Now tell me this – speaking of that support system, because others have definitely mentioned the support. Some have mentioned maybe a benefit of having a support system even at the centers, like a support group among like patients. What do you think about that?

S: *I think it would be nice because everybody – even, you know, some people at the, at the clinic, they don't have a support system at home. They don't – some of them don't have anybody really, you know, and then you get some people that's in these, um, what they call them? These – what's them – um, nursing homes that comes down, that comes to the clinic, and a lot of those people don't even have people to talk to anymore because they family members don't even be involved in their life. I guess they put them in a home and just leave them, and that's where they stay, and so when they come down to dialysis, that's basically the only kind of support that they have or people to talk to about they problems because it's basically – I mean you part of they family because you're there four hours a day. So it's like half your day of there. So it's just like having a – basically a support family down there, but it's just you can't interact with each other because you're on a machine.*

PI: Yeah.

S: *So it, you know, kind of limit yourself to that, too, of really kind of talking to a lot of people – the people that's down there because you, you know, you can't get around. You can't down. You know, you can't get up and actually talk to them. You got to talk down the hall from beds.*

PI: Hmm-hmm. So would it be important if there was some time where some folks could actually group together who are not on the machines, in a private room.

S: *Who want to talk – yeah. It would be nice because, you know, you – basically I think that all, all dialysis patients need some kind of support because even the ones who got support at home because sometime a lot of people don't understand how it is being on the machine because they ain't that machine. They don't how that machine actually make you feel, even after you get off of it. They don't understand that the – even though you're going through a process and they just saying, "Oh, they cleaning your blood out," you know. But they don't understand the effects of it afterwards when you get off of it because you be so tired, so drained where you leave – sometimes you have to come home no matter what at least to get two or three hours of sleep just to kind of build the energy back up in your body.*

PI: Hmmm.

S: *You be so weak where you can't even pick up like five, ten pounds because you so weak. Can't even open a bottle, because it's been times I been like that. I can't even open a bottle just to open my juice.*

PI: Okay

S: *You know, but people on dialysis understand that because they go through it. They go through it three days out of a week. People that don't have those physical problems, they don't understand that.*

PI: Okay, okay. How would you compare yourself to men who are not on dialysis?

S: *Well I just call them the privileged young men because they still active. They can still do what they want do. They don't have themselves. They can eat them a bowl of ice cream when they want to. I used to love ice cream. Cereal, I – they, you know, they can eat all the cereal they want to. I used to could a box of cereal in one day.*

PI: Okay.

S: *You know where – I used to love milk. I could drink a gallon of milk in two days, which I can't do that no more. Um, it's just that they should be happy they ain't on dialysis because when you get this route, you got to limit yourself to a lot of things and a lot of people don't like limiting themselves.*

PI: Hmm, so it takes away your control?

S: *Yeah. You got to have good control to be on dialysis because I done seen, you know – like one particular time about three years ago, it was a young guy. He had to been about – I think about 38, 40. I hate this happened to him. He passed away at the dialysis unit, but he had just got on dialysis and they kept telling him to stop eating all the potatoes. Thanksgiving came around. He ate – he was a big guy, though. He was about 300, 6-4, but they kept telling him to don't – they told him to limit himself. If you want a piece, just cut one. He ate two sweet potato pies and a gallon of milk. So you know what happened to him.*

PI: Okay.

S: *And he kept doing it. I even kept telling him. I said, "Man, you don't wanna keep doing that. Something gonna happen to you." He came in, weighed himself and he...*

PI: Okay. Let me ask you this. How do you think that any of the concerns that you mentioned would be different if you were not African American?

S: *Do I? Hmm, that's a good question. I never had anybody ask me that. Uh, I don't think so.*

PI: Okay.

- S: *Because I think it would – I think it – by me being on it – I think that affect everybody basically the same way, because you know it depends – due to the situation that – because everybody, men that I have talked to that actually been on dialysis – I done talked to White, you know. I done had a few Asian men that's been in there, Black, and basically all of them tell me basically the same thing. The first year or two it was okay, but it dwindled from that. The affect dwindled, you know, it dropped from that. So it's not – I think it's just the medication and the – the treatment we're going through. That's the – that's what's doing it and it could be, it could be – like I said, it could be the medications because it could take away the stimulation of your sexual drive, which I know they say all medications have some kind of side effects, and you don't know how much damage it does to you regardless. I mean it's helping you live, but it might take that urge away.*
- PI: Okay. Now let me ask you this. I heard you focus on problems with sexual drive. Do you think, in your opinion, do most men consider that the sexual drive is the biggest component of the taking away from manhood secondary to dialysis?
- S: *Yes. I mean, I mean, if you're a man, I mean, and you enjoy women. I mean I know it's not always about sexual, but the sexual aspect of it is like 50 percent of the time regardless. I mean you enjoy the company. You enjoy the time you spend with that particular person. You, you know, you enjoy the finer things, going out to dinner and all that, but the physical aspect of it, I mean, you, you would love to enjoy that particular part, too, no matter what. I mean when you're on dialysis, like I said, it's in your brain but it just don't function down there, and that's what actually gets me mad because I get upset sometime when it doesn't function right, and I have to take some medication and still wait 45 minutes to – which before then I didn't even have to do that. You get me sexually aroused, I could just – I could just enjoy myself, but by – see and if you don't have a patient woman that don't understand what's going on with you, she gets upset about it.*
- PI: Okay.
- S: *You know and a lot of women – I can't say all but a lot of women don't understand that, and the first thing they want to do is say forget it if they can't continue enjoying themselves.*
- PI: Oh, okay.
- S: *They just say forget it. I don't even want to be bothered no more now, and it makes you, gets you in arguments. It upsets the house and I went through that for the first time in my life, but me and my wife got better.*
- PI: Okay.
- S: *We understand each other now, where if you don't – if your mate don't understand, you probably will be sitting outside going somewhere else to live.*

PI: Is this something that health care providers might help with by even talking to the mate and giving more information as to some of the things that happen, do you think?

S: *I really don't think it's the provider that needs to do it. I think that the husband or if they give the mate that's on dialysis some literature or something to bring home for that particular person to look at and understand what's going on where it will tell you that, you know, due to such and such and such and such, sexual drive will drop, this, this and that, which they can understand and see it in black and white instead of them just telling them that.*

PI: Okay.

S: *Because sometimes even though you tell your mate and that, and they don't see the literature on it, they will think that you out cheating. It's not you out cheating. It's not you out wanting somebody else. It's just that the sexual drive is not there anymore because of the – because you're on dialysis and it's taken away your ability to do that.*

PI: Okay, okay, okay. What else would you like health care providers to understand about the affect of dialysis on being a man?

S: *Well, me, I would want them to understand exactly what goes on with a person because for one, sexual. It's also a mental thing because it can be mentally real stressful and, I mean, that they don't understand that – to them it's just medical. It's not. It's physically. It's family oriented, because a lot of times, even when you're on dialysis, it breaks up home, and you got kids, you got a wife. It will break up your home if they don't understand everything that's going on, and that, I mean, like I said, finance – it really – okay, you do, financially, physically because if your mate not happy physically and mentally happy, things will get rocky and it go downhill quick and people don't like being depressed and upset like that all the time, and eventually it will happen. You will get divorced. You will get – you'll be separated. The kids be wondering what happened, um, because due to situations like that. But they don't understand that. They only looking at dollars and cents to me.*

PI: Hmm. Tell me this. What can help them to understand that? You mentioned that most times you see the health care providers – the nurses, the physicians, the social workers – when you're in the chair and that's not a private occasion.

S: *Right.*

PI: You also mentioned that you think most men have a hard time bringing up sexuality concerns unless it's initiated by the health care providers themselves.

S: *Right.*

PI: How do you think that – what should be done to help them understand some of these things?

S: *What about – I mean, like when they do they – okay they do a – they call it a – every year they do a six-month evaluation. Every year they do – so they do it twice a year.*

PI: Okay.

S: *So when they come around for you to sign out these – it's some sheets they have you sign telling you, "Have your insurance changed, your address?", anything like that. When they come around and talk to you about that, they should ask you do you have any concerns or any other problems that you need to talk to...if you do, come and see me in my office.*

PI: Ahh, okay.

S: *You know that way it could be a private matter and you don't have to...*

PI: Okay.

S: *Because like I say, a lot of people don't want to talk about private things around other people. They rather that it be between one, you know, you and that particular person.*

PI: Okay. Do you think they should also, sort of list out some of those options for concerns on that form, so that you could freely respond about family or a physical sexual relationship, etc?

S: *Yeah, I mean, that would be nice to have a form. That way when they get ready to come in, you would understand what's going on instead of just being in the dark and waiting until that particular person come in and be like, "Okay, what do you need to talk to me about?" That would be nice.*

PI: Right, I think that I cut you off a moment ago, when I asked you what else would you like health care providers to understand. Is there anything else?

S: *Well, they, um, they kind of, to me, where I've been going, they been pretty okay with me. I can't say about everybody else but they been pretty okay with me. It's just that I would love for the health providers to understand that if a man get where – to me it's like – it's a sexual thing. If they can give you medication or try to guide you somewhere – because see I was looking at a program on TV. It's called "Doctor...something". It was on TV and I didn't know they could do all this, but they can put – insert a, it's like balloon or something in your penis and you can pump it up.*

PI: Hmm.

S: *See I didn't know that, but if – by a person being on dialysis and they just limit they self, they should be able to – where they can make it more affordable to a person that's dialysis. You know, not just for, you know, people that's got money to afford that because even though a person that don't have money or is less fortunate, you know, they still would want to keep their families together, too – not just the rich.*

PI: Okay.

S: *And that was something I was thinking about looking into myself. Because of that situation, but when I looked into it, I think they said it costs three, four, five thousand dollars, something like that. I don't have that kind of money, and I know my, my insurance is not gonna pay for it because I looked into it.*

PI: Hmm.

S: *But I was doing okay with the, with the pills for a minute until they stopped giving me them. But see if, uh, like the doctors we got that come in there – our kidney doctors and stuff, our physicians, if they can get – because I know they deal with a lot of medication companies. If they can get the medication to donate, you know, like Viagra. But if they could get them to donate the stuff, where they can give samples to the patients.*

PI: Hmm.

S: *You know where it can keep them where they don't have to come out of pocket all the time, you know. But I know them kind of companies, they all about money, you know.*

PI: Okay.

S: *It's some companies they, they do look out for the people, but a lot of them is all about the money. If you can't afford it, you can't get it.*

PI: Hmm, okay. So something else to put on that six month form, huh?

S: *Right, and that would be a good thing because, you know, if you – like I say when I, when I was – when it really start happening to me bad, and they was giving me the 10 pills, they would allow you 10 pills a month. That was good. Shoot, that's a hundred dollars. Well actually two hundred because they \$20.00 apiece. Because I done bought some since then, but I mean, you know, you spending \$20.00 every time just to get one. You know, and it seem like if you on dialysis or something and you low income, at least give them a break or something. They don't want to give you even that, and you know it's nothing generic out here for those. It would be good if it was generic, but you know, they keeping the patent for themselves. I mean, you know, that's the thing. They keeping it for they self because it's a what – what they say? A billion dollar operation.*

PI: Right.

S: *Oh I look up my stuff before I do anything.*

PI: Okay.

S: *I said they making billions of dollars off this little bitty pill and they can't afford to give samples out. (pause)*

PI: (pause) Is there anything else that you'd like to add?

S: *No because most of the companies – most of the pharmacy that I know my doctor deal with – I don't know who – you know, I know the doctors probably deal with all of them but my doctors is pretty okay because they do ask me certain stuff because that's how found out about the Viagra because my doctor asked me, "Is it limiting you sexually?", and I was like, "Yeah." She was like, "Well do you want me to get you some Viagra?", and she got me some, but then she said they stopped giving them to her, and then that's when she was like, "Well I'm gonna see if I can get you 10 pills a month. The government pays for them." It was being paid for then, then they just stopped that.*

PI: Hmm.

S: *Then when I told her, she said – she kept saying, you know, "Do you got any?" She said, "No, I'm still waiting for them to send me some more, see if I can get some more." She said, "When I get them I'll give them to you." So she's been pretty – she – they been pretty okay with me.*

PI: Okay. (long pause) Is there anything else you want to add?

S: *Hmm, no. I can't think of nothing else.*

PI: Okay. Well we will stop now; thank you.

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ABSTRACT**PERCEPTIONS OF SEXUALITY BY AFRICAN AMERICAN PATIENTS ON
HEMODIALYSIS**

by

MERRY STEWART**May 2010****Advisor:** Dr. Ramona Benkert**Major:** Nursing**Degree:** Doctor of Philosophy

Sexuality is central to who we are as sentient beings and transcends physical sex acts. Sexuality concerns are reported as common for individuals receiving hemodialysis; yet, sexuality-related research for this population has been limited to a focus on altered physical sexuality. Little is known about the effects of hemodialysis on perceptions of personal identity, family-social roles as men or women, and intimate relationships. African Americans make up a disproportionate percentage of chronic hemodialysis patients and may be at greater risk for altered sexuality. The purpose of this qualitative descriptive study was to explore African Americans' perceptions of sexuality since being on dialysis. A middle-range model, the Sexuality Adaptation Model (SAM), derived from Roy's Adaptation Model provided a guiding theoretical framework. Semi-structured interviews were conducted with 19 African American men ($n = 12$) and women ($n = 7$) who were receiving hemodialysis treatment (mean age = 49.95 years). Eight participants (seven men, one woman) were married, or in steady relationships. The range of dialysis years for the participants ranged from 1 to 10 years ($M = 4.16$, $SD = 3.08$). For male participants, a strong endorsement of traditional masculinity ideology was found to promote adaptive behaviors that minimized an altered sense of "who I am" as a man. In contrast,

female participants' perceptions of sexuality were found to be influenced by multiple meanings of their identity as Black women. Most partnered men expressed greater concerns regarding the effects of hemodialysis on diminished physical sexuality and altered partner relationships, whereas women participants were primarily concerned about their altered personal sexuality identities and roles as a mother. The rollercoaster effects of loss of time, energy, independence, and negative dialysis center environment was suggested to erode perceptions of sexuality among the majority of study participants. Informal mutual support groups were reported to contribute to positive perceptions of sexuality. The application of the SAM facilitated relevant descriptions of participants' perceptions of sexuality and supported the investigator's assertion that a holistic approach is needed to guide research and clinical interventions related to sexuality concerns.

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