

**PREDICTORS OF QUALITY OF LIFE OF ELDERLY END-STAGE RENAL
DISEASE PATIENTS: AN APPLICATION OF ROY'S MODEL**

by

CELIA G. HAY

A DISSERTATION

**Presented in Partial Fulfillment for Requirements of the
Degree of Doctor of Philosophy in Nursing in the Byrdine F. Lewis School of
Nursing in the College of Health and Human Sciences
Georgia State University**


Atlanta, Georgia

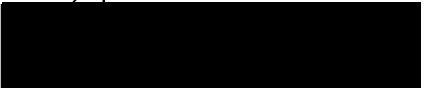
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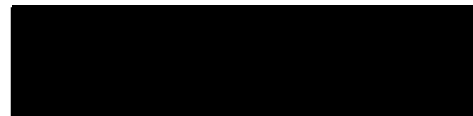
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ABSTRACT

PREDICTORS OF QUALITY OF LIFE OF ELDERLY END-STAGE RENAL DISEASE PATIENTS: AN APPLICATION OF ROY'S MODEL

by

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There is increasing recognition that what matters most to chronically ill patients is how well they are able to function and how they evaluate the quality of day-to-life. Understanding the impact of chronic illness and associated treatment on functioning and well-being in the physical and psychosocial dimensions of older people's lives is essential. In 2004, over half of all new patients starting dialysis were 65 years of age or older (USRDS, 2004). The physical and psychosocial impact of end-stage renal disease may lead older hemodialysis patients to withdraw from treatment and die from uremia, rather than live with seriously diminished QOL.

The purpose of this study was to test a theoretical path model of the effects of age, income, gender, education, time on dialysis, functional health status, spirituality, powerlessness, and depression on the perceived of quality of life of the elderly end-stage renal disease patients. Roy's Adaptation Model was used as a theoretical framework to guide the identification of the factors that predict the quality of life of elderly ESRD patients.

The study sample consisted of 79 in-center hemodialysis patients over the age of 65. Five self-report instruments and researcher-developed demographic and medical data

questionnaires were used. The instruments included the Inventory of Functional Status-Dialysis (IFS-D), Religious Coping Scale (R-COPES), Life Satisfaction Index-Z (LSI-Z), Center for Epidemiological Studies-Depression (CES-D), and Health-related Powerlessness Scale (HRPS).

The final path model showed that the role function mode (total functioning), self-concept mode (depression and spiritual coping) all had significant and direct effects on quality of life. The interdependence mode (powerlessness) had a significant direct effect to quality of life and a significant indirect effect through the role function mode. Together these variables explained 68% of the variance in the quality of life of older hemodialysis patients. The role function mode (total functioning) had the strongest influence on quality of life so that the greater the level of functioning the better the quality of life. Lower levels of depression and powerlessness and the use of spiritual coping along with higher levels of total functioning positively influenced the quality of life and formed a trimmed path model in this study.

These findings provide an initial direction for further theory refinement and suggest that there should be a focus on the development of nursing interventions that include physical and psychosocial variables with elderly dialysis patients in order to improve their quality of life.

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ACKNOWLEDGEMENTS

There are many people who contributed to the successful completion of this study. I would especially like to thank my Committee Chair, Dr. Carolyn Kee, who guided me through the dissertation process with such expertise, and Dr. Ptlene Minick and Dr. Cecelia Cantrell for their much needed advice and support throughout this project. I appreciate the time commitment involved and friendship over the past several years.

I appreciate very much the financial support provided by LaGrange College. I also want to thank my friend and colleague, Dr. Maranah Sauter, for giving me the time I needed and for offering a sympathetic ear.

I wish to thank the people whose stories are a part of this research. They were all so giving of their time. I also appreciate the nephrology nurses and social workers who aided in my understanding of this unique group of special people.

And finally, this dissertation is dedicated to my family, Buddy, Ryan, and Matthew for their support and understanding. Thank you for constantly rearranging your lives to suit my aspirations and always being there for me.

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LIST OF ABBREVIATIONS

ESRD	End-stage Renal Disease
RAM	Roy's Adaptation Model
QOL	Quality of Life

CHAPTER I

INTRODUCTION

Questions about what constitutes a good life have been debated throughout the ages. The term quality of life is of a more recent origin. Social scientists began to use the term in the 1970's, and since that time there has been a growing interest in quality of life issues for medicine, nursing, and other healthcare disciplines. One of the explanations for this growing interest has been the increasing numbers of elderly people in society. Increasing age often brings about chronic health problems and a decrease in functional capacity. For those persons, the goal of healthcare is not to be free from disease, but to maximize functional ability and overall well-being. The elderly population, with many psychosocial changes within their lives due to the aging process, can be identified as a group experiencing stressful changes with regards to chronic illnesses. This aging cohort may need to be given special attention by healthcare professionals in order to reach adaptation.

The End-stage renal disease (ESRD) program of Medicare is truly an American success story. The implementation of a complex, life-sustaining technology (hemodialysis) has made it possible for treatment that is financially supported and widely available. Persistent clinical challenges among ESRD patients include improving mortality and morbidity outcomes as well as maximizing life quality.

Potential candidates for renal replacement therapy continue to grow as the population ages in the United States. Both the incidence and prevalence of ESRD increase dramatically with age. By the end of 2002, patients age 75 years were the

largest incident age group and those between 65 and 69 years were the largest prevalent age group (United States Data System, 2004). In the United States, 110,274 ESRD patients over the age of 60 years are being treated by chronic hemodialysis in outpatient dialysis clinics.

Despite rapid technological advances in the treatment of patients on hemodialysis, most patient treatment-related stressors have not been eased by technology (Welch & Austin, 1999). The hemodialysis machine is a lifesaver, but not a cure for ESRD. Hemodialysis becomes a vital part of the lives of ESRD patients. Most must receive hemodialysis treatments three times per week. The need for such an invasive therapeutic measure to maintain life affects health and virtually all other aspects of these individuals' lives. In addition, they must deal with problems related to hemodialysis and the illness itself including fatigue, muscle cramps, fluid limitations, added financial burdens, impotence, changes in physical appearance, uncertainty about the future, and limits on time (Baldree, Murphy, & Powers, 1982; Gurklis, 1992; Stapleton, 2000; Patel, Shah, Peterson, & Kimmel, 2002).

Quality of life has been recognized as a relevant issue for nursing (Padilla, Ferrell, Grant, & Rhiner, 1990; Ferrans & Powers, 1985; Sarvimaki & Stenbeck, 2000), but there is no agreement on the definition of QOL and on what should be measured. Sarvimaki and Stenbeck-Hult (2000) described the variables of health, living environment, and economic situation as having the strongest influence on an older person's quality of life in general. However, Jaloweic (1990) found that psychological well-being is viewed as the most important variable in determining QOL. Although QOL issues are relevant to all

aspects of nursing, they are probably more relevant in the care of older people with chronic illness. However, in order to investigate how health care providers can improve quality of life in their elderly patients, we need to know how to characterize quality of life and which factors influence the QOL of elderly hemodialysis patients.

Purpose

There is increasing recognition that what matters most to chronically ill patients is how well they are able to function and how they evaluate the quality of day-to-day life. Thus, understanding the impact of chronic illness and associated treatment on functioning and well-being in the physical, mental, and social dimensions of older people's lives is essential. Efforts to incorporate quality of life assessment into healthcare outcome studies are increasing. In 2004, over half of all new patients starting dialysis were 65 years of age or older (USRDS, 2004). Because these patients tend to have other concurrent medical problems such as diabetes or heart disease, the physical complications of these patients on dialysis may be great. The physical, psychological, and social impact of these problems may lead older hemodialysis patients to withdraw from dialysis and die from uremia, rather than live with seriously diminished QOL (Singer et al., 1995; Badzek et al., 2000). In fact, withdrawal from dialysis is the second most common cause of death in dialysis patients over the age of 65 years and the most common cause in those dialysis patients over 70 (National Institutes of Health, 1999). The purpose of this research study is to test a theoretical path model of the effects of age, income, education, gender, time on dialysis, functional health status, spirituality, powerlessness, and depression on the perceived quality of life of elderly hemodialysis patients.

Assumptions

The following assumptions are made regarding this study on the quality of life issues of older hemodialysis patients:

1. A good quality of life is a priority for most people.
2. Older hemodialysis patients want to assume control of their own health experience.
3. There are identifiable physical and psychosocial aspects of the older hemodialysis patient that influence their perceptions of life quality.
4. Perceptions made by older persons receiving hemodialysis treatment accurately reflect reality.

Theoretical Framework

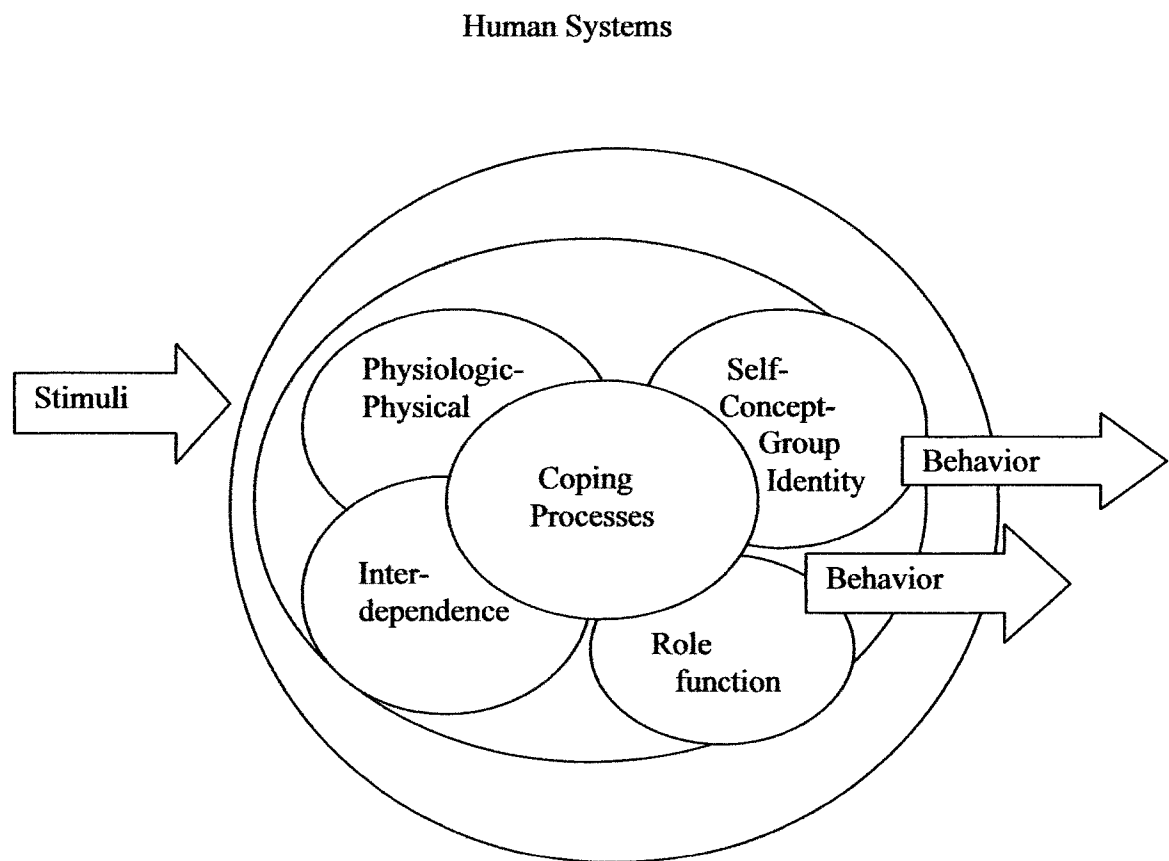
Roy's Adaptation Model (RAM) can be used to frame a study on quality of life of older hemodialysis patients because it explicitly focuses on how individuals cope both physiologically and psychologically with environmental change. From its early beginnings in the late 1960's when Sister Callista Roy was a graduate student, the RAM has evolved over the past 32 years. The first publication on the model appeared in the nursing literature in 1970 (Roy & Andrews, 1999). The RAM views the person as an adaptive system. Three major concepts of the RAM are stimuli (focal, contextual, and residual), coping mechanisms, and behaviors (physiological, self-concept, role function, and interdependence).

Within the Roy Adaptation Model (Roy & Andrews, 1999), man is described as a holistic adaptive system, whose parts are interrelated and function as a whole. This adaptive system receives inputs, termed stimuli by Roy, from internal and external

environments. Inputs are described as focal, contextual, and residual stimuli. Together the three classes of stimuli contribute to the individual's adaptation level. Behavioral responses to these stimuli are deemed to be adaptive or maladaptive. Figure 1 depicts the person as an adaptive system as proposed by Roy.

Figure 1

The Person as an Adaptive System.



Adapted from Roy, C. & Andrews, H.A. (1999). The Roy Adaptation Model: The definitive statement (p. 50). Norwalk, Connecticut: Appleton & Lange.

Focal stimuli are described by Roy and Andrews (1999) as “the internal and external stimuli most immediately confronting the individual - the event that attracts the individual’s attention” (p. 31). For example, the diagnosis of a chronic illness such as ESRD requiring hemodialysis in order to live may be a focal stimulus. The individual’s perception of the focal stimulus and how she or he copes with this stimulus are influenced by past experiences with identical or similar stimuli.

Contextual stimuli are “all other stimuli present in the situation which are known to contribute to the effects of the focal stimuli” (Roy & Andrews, 1999, p. 31). Contextual stimuli influence the meaning people attach to a situation. Common examples of contextual stimuli include age, SES, family structure, perception, knowledge, and beliefs. For example, a response to being on hemodialysis may be influenced by the belief that hemodialysis will prevent travel during retirement.

Residual stimuli “are environmental factors whose effects in the current situation are unclear” (Roy & Andrews, 1999, p. 31). For example, a person’s spiritual beliefs may or may not provide hope and meaning and influence a person’s ability to cope with a chronic illness.

According to Roy and Andrews (1999), the nature of a given stimulus may change. A focal stimulus may become a contextual one or a contextual stimulus may become a residual one depending on conditions.

Coping processes are “innate and acquired ways of responding to and influencing the changing environment” (Roy & Andrews, 1999, p. 46). Innate coping processes are genetically determined. These processes are automatic and unconscious. An example

would be the body's ability to regulate hemoglobin. A person does not have to think about it for it to occur.

Acquired coping processes are learned responses brought on by experience. These responses are "deliberate, conscious, and acquired" (Roy & Andrews, 1999, p. 46). We learn through the experiences of life how to respond to certain stimuli.

When dealing with the individual as a human adaptive system, the RAM conceptualizes these innate and acquired coping processes into two subsystems, the regulator and the cognator. Stimuli from the environment serve as input to the person's regulator and cognator subsystems. The regulator subsystem responds to environmental stimuli automatically through neural, chemical, and endocrine coping processes. Inputs to the regulator play a role in forming perceptions and linking the regulator to the cognator. An example of regulator activity is an automatic change in size of the pupils as a reaction to the amount of light in a room.

The cognator subsystem responds through "cognitive-emotive channels: (a) perceptual/information processing, (b) learning, (c) judgment, and (d) emotion" (Roy & Andrews, 1999, p. 46). Selective attention, coding, and memory are within the perceptual/information processing channel. Roy and Andrews (1999) describe perception as the interpretation of a stimulus. Therefore, perception provides meaning to what is sensed by a person and links the cognator to the regulator. Perceptions are influenced by contextual and residual stimuli. For example, perception of pain may be influenced by whether pain is accompanied by other symptoms such as nausea and vomiting. Perception may also be influenced by past experience with pain.

Learning, another cognator activity, involves insight, reinforcement, and imitation. Judgment, a third activity of the cognator subsystem, includes the processes of problem solving and decision-making. Additionally, through the cognator's emotive channel, emotions that are difficult to deal with may be avoided by the use of defense mechanisms such as denial.

According to Roy's model, behavioral responses to focal, contextual, and residual stimuli can be observed within four modes of adaptation (Roy & Andrews, 1999, p. 31). The four modes are physical, self-concept, role function, and interdependence. Figure 1 shows how stimuli provoke coping mechanisms which ideally result in adaptation responses. Adaptive responses are behaviors which are effective in terms of survival, growth, mastery, and reproduction.

Behavioral responses are considered to be the outputs of the person and result from cognator and regulator processing of stimuli. Behavior is defined as "internal or external actions and reactions" in all situations, not just those indicative of health problems (Roy & Andrews, 1999, p. 67). Behaviors can be adaptive or ineffective. Adaptive behaviors are those that promote the integrity of the person in terms of the goals of adaptation: survival, growth, reproduction, and mastery (Roy & Andrews, 1999). Ineffective behaviors are those that do not promote the goals of adaptation. Judgments about the effectiveness of a client's behavior can be made by the patient or the patient and nurse working together.

The actual processing of stimuli by the regulator and cognator may not be observed directly, but results of their activity (behavioral responses) are observed within

the four adaptive modes (physical, self-concept, role function, and interdependence).

Behaviors observed in the four modes indicate cognator and regulator activity within the adaptive process. Each of the adaptive modes is described below.

The physical mode is the means by which the person responds to stimuli as a physical being. Behaviors observed in the physiological mode reflect a person's efforts for oxygenation, nutrition, elimination, activity, rest, and protection. The goal of behavior in the physical mode is physiological integrity.

The self-concept mode focuses on psychological and spiritual aspects of behavior. It is described as what a person believes or feels about the self at a given time (Roy & Andrews, 1999). A person's self-concept is formed from internal perceptions and the perceptions of others and directs human behavior. The physical self and the personal self are two components of this mode. Behavioral responses in the self-concept mode are directed toward the goal of psychic integrity.

The role function mode involves the way a person responds to environmental stimuli relative to their roles in society. For example, the way an older person with ESRD might perceive fatigue and the way a health professional might perceive fatigue could be quite different. The older person might view fatigue as an expected accompaniment to being old and view it as a normal response. A nurse in dialysis might view the fatigue as a symptom of the hemodialysis treatment. Both the nurse and the older person with ESRD have learned appropriate ways to respond in a given situation. The manner in which a person fulfills his or her social roles provides an indication of the level of social integrity, the goal of behavior in this mode.

Behaviors indicative of the interdependence mode are those relative to giving and receiving love and respect. The goal of behavior in this mode is affectional adequacy. Feeling secure in nurturing relationships is an example of affectional adequacy. The relationships important to this mode are ones involving significant others and support systems.

Roy and Andrews (1999) propose that these four modes are interrelated. A behavior within one mode may act as stimulus for each of the other modes and thereby affect behavior. For example, a grandmother hospitalized with ESRD may not be able to carry out her role as a grandmother. This may change the way she feels about herself and cause her to suffer from depression and low self-esteem.

A person's behavior, as the output of the human system, acts as feedback input to the system. Feedback from the initial coping behavior gives the person a chance to decide whether that behavior is sufficient to deal with the focal stimulus. If the initial response is not adequate to cope effectively with the stimulus, other coping mechanisms are activated to produce additional responses (Roy & Andrews, 1999). A focal stimulus that a person can easily manage elicits the person's usual ways of responding to stimuli.

Summary

A large number of older ESRD patients survive for only a short time on dialysis because of multiple comorbidities. Voluntary withdrawal from dialysis treatment is another pressing problem. The rate of voluntary withdrawal from dialysis is much higher among older patients (Kutner & Brogan, 1992). A related concern, about which there is little information, is the level of physical functioning and psychosocial well-being of

older hemodialysis patients. Physical functioning and psychosocial well-being are important parts of an older persons' life quality. Quality of life has been shown to be important not only as an outcome of medical care for ESRD patients, but also a predictor of survival. As health-care providers increase their use of outcome information to improve medical care for older ESRD patients, more information is needed on what constitutes the quality of life for these patients. Roy's Adaptation Model serves as a guide for examining of the relationships between age, income, time on dialysis, gender, education, functional health status, spirituality, powerlessness, and depression of older hemodialysis patients. It is important to determine factors influencing the quality of life of older hemodialysis patients in order to provide improved interventions that would impact the clinical outcomes for this growing population.

CHAPTER II

REVIEW OF LITERATURE

There is considerable literature related to the notion of quality of life in the chronically ill patient. The focus of this chapter will be to review the relevant literature pertaining to the quality of life of hemodialysis patients. The concepts of functional health status, social support, powerlessness, depression, and spirituality in people dealing with end-stage renal disease are included. The conceptual definitions that are used in this study are delineated at the end of this chapter.

Quality of Life

Quality of life (QOL) assessment has become increasingly important in research, especially for such chronic conditions as end-stage renal disease. Since there is no agreed upon definition, inconsistent interpretations of what actually constitutes QOL remain confusing. The following synopsis exemplifies the numerous variables used in the measurement of QOL: (a) physical well-being, health, and functional status (Ferrans & Powers, 1985; Padilla & Grant, 1985; McClellan, Anson, Birkili & Tuttle, 1991); (b) symptom control (Padilla, Ferrell, Grant & Rhiner, 1990); (c) psychological well-being (Lawton, 1983; Patel, et al., 2002); (d) self-esteem, self-worth, or self-concept (Deyo, 1991; Walters, Hays, Spritzer, Fridman & Carter, 2002); (e) attitude toward self, life or future (Stewart, 1992); (f) internal control and/or coping (Hinds, 1990); (g) spirituality (Ferrans & Powers, 1992; Haas, 1999; Patel, et al., 2002); (h) financial adequacy or

socioeconomic status (Zahn, 1992), (i) social support, social network, and/or social activity (Burkhardt, 1985; Zahn, 1992), and (j) happiness, fulfillment, goal attainment or life satisfaction (Salvimaki & Stenbock-Hult, 2000).

Because of the multiple stressors of renal failure and the loss of lifestyle, the concept of quality of life (QOL) is an important issue for hemodialysis patients (Ferrans & Powers, 1992; Thomas, 1992; Lok, 1996; Kutner, Brogan, Hall, Haber, and Daniels, 2000; Mapes et al., 2003, Tell et al., 1995). The concept of QOL has been used in research for several decades. There is no agreed upon definition but a growing consensus is emerging concerning which domains should be included. Thus, quality of life assessment should include the areas of physical, psychological, social functioning, intellectual functioning and general satisfaction with life (Sullivan, 1998).

Oldenburg et al. (1988) examined the physical, psychological and social impact of end-stage renal disease on the quality of life of 102 patients. The results revealed that hospitalized patients on dialysis and the length of time on dialysis were predictive of more psychosocial stress when compared to patients who were outpatient dialysis patients. Kutner et al. (1992) looked at quality of life early in dialysis treatment and related it to exercise activity. This study included 226 patients who were in their first three months of treatment. No significant relationships were seen between early versus late diagnosis of renal failure diagnosis and quality of life. Associations with quality of life were seen, however, for several demographic variables as well as for primary diagnosis of diabetes, cardiovascular comorbidity, dialysis modality, and patient-staff ratio.

Evans et al. (1985) investigated the quality of life of 859 patients with end-stage renal disease. Renal transplant patients reported the highest quality of life followed by those undergoing hemodialysis at home, whereas CAPD and patients who had hemodialysis in outpatient centers had lower quality of life values. Bremer et al. (1989) reached similar conclusions except for patients who had a failed kidney transplant and were back on hemodialysis. This group scored lower than did dialysis patients without a previous failed transplantation. Lok (1996) found that quality of life was perceived as below average in both hemodialysis and CAPD patient groups, but the latter group experienced a higher quality of life than those on hemodialysis.

Functional Health Status

Functioning, that is, the ability to perform and the actual performance of usual activities, is a particularly important aspect of quality of life for patients with end-stage renal disease (Churchill et al., 1987; Molzahn, Northcutt & Dossetor, 1997; Stegman et al., 1985). Moreover, there is a strong relationship between level of functioning and survival in chronic dialysis patients (Carlson, Johnson, & Kjellstrand, 1987; Husebye et al., 1987; Kutner & Brogan, 1992; Kutner, Fielding, Brogan, 1994; McClellan et al., 1991).

Investigations of functioning in chronic hemodialysis patients have focused primarily on functional ability, that is, the ability to perform usual activities. Research findings have consistently demonstrated that chronic hemodialysis patients' ability to function is impaired (Bjorvell & Hylander, 1989; Carlson, et al., 1987; Evans, 1991; Evans et al., 1985; Gutman, Stead, Robinson, 1981; McClellan, Anson, Birkeli, Tuttle,

1991; Tell et al., 1995) and a significant number of patients are unable to perform routine daily living activities independently (Gutman et al., 1981; Ifudi et al., 1995). For example, it has been reported that patients on chronic hemodialysis demonstrate an exercise capacity that is less than 40% to 50% of that predicted for normal age and sex-matched individuals (Goldberg, Hagberg, Delmez, 1980; Painter & Zimmerman, 1986; Robertson, Rapoport, & Goldberg, 1986). Moreover, Ifudi et al. 1994 noted that up to 36% of in-center hemodialysis patients required assistance with routine daily activities. In addition, Evans (1991) noted that only 44% of in-center hemodialysis patients were capable of normal physical activity. Thus, much of the research regarding functioning in hemodialysis patients has focused on the extent of functional ability in this population.

Chronic in-center hemodialysis patients' level of performance of occupational activities has been well documented. In what has been considered a seminal investigation of the employment status of 2,481 chronic dialysis patients, Gutman et al. (1981) found that only one-quarter of the patients worked outside the home. Similarly, a rigorous examination of 859 ESRD patients' quality of life revealed a labor force participation rate of 67% prior to the onset of dialysis compared to 35% after the onset of ESRD (Evans et al., 1985).

Four studies were found that explored chronic in-center hemodialysis patients' actual performance of daily non-work activities. Julius et al. (1989) examined both the ability to perform and actual performance of self-care and household activities in a sample of 459 in-center hemodialysis, continuous ambulatory peritoneal dialysis, and successfully transplanted patients. The only outcome measure reported was the extent to

which patients were able to perform those activities. Similarly, in Killingsworth and Van der Akker's (1996) investigation of chronic hemodialysis and continuous ambulatory peritoneal dialysis patient's ability to perform and actual performance of self-care and household activities, the patients' actual ability to achieve independence in activities of daily living was the only outcome reported.

Wolcott and colleagues (1988) investigated 66 chronic dialysis patients' quality of life and examined their current level of participation in physical, sedentary, and community-based activities. Patients' responses indicated that they maintained a moderate level of participation in sedentary activities, a minimal level of participation in active physical activities, and low levels of participation in community and social activities.

In a study to develop and test a functional status instrument, Thomas-Hawkins, Fawcett, and Tulman (1997) examined the actual performance or non-performance of personal care, household, and social and community activities in a sample of 175 chronic in-center hemodialysis patients. Inasmuch as there were inconsistent judgments made by chronic in-center hemodialysis patients during content validity testing regarding the relevance of occupational activities to this population, the performance of occupational activities was not examined. Relatively low total functional status scores and subscale scores on personal care activity, household, and social and community activity ranging from low to high underscore the need for further examination of this populations' level of functional status. Therefore, further research is needed to better understand the functional status of older hemodialysis patients.

Only one investigation was found specific to the older dialysis population and functional health status. In a prospective cohort study over three years, Kutner, Brogan, Hall, Haber, and Daniels (2000) examined functional health status in 113 in-center hemodialysis patients over age 60 and 286 age-matched controls. Compared to the controls, dialysis patients reported significantly more functional impairment at baseline and at the three-year follow-up after adjusting for baseline impairment and covariates.

In this study, functional status focuses on the roles the person occupies in society with attention on the ability to perform activities associated with their different roles. This definition follows Roy's role function mode of adaptive behaviors.

Powerlessness

Maslow (1968) pointed out that the authentically healthy person is not defined by individual autonomy. The healthy person needs the ability to master the environment: that is, to have power over it. Conversely, Miller (1992) defined powerlessness as the "perception that one lacks the capacity or authority to act to affect an outcome of the current situation or immediate happening" (p. 52).

The concept of powerlessness has been closely related to the construct of locus of control (Johnson, 1967). According to Rotter (1966), locus of control is a relatively stable personality trait dependent upon the individual's perception of the controlling phenomena of events. These controlling phenomena are classified as being either external or outside the individual, or as being internal and dependent on the individual's own behavior. An individual with an external locus of control relies on luck or chance, while an individual with internal locus of control believes that personal behavior, effort

or skill will affect a desired outcome. The former is an example of a powerless individual while the latter is an example of an individual who has or is seeking power.

Miller (1992) viewed powerlessness as markedly different from Rotter's conceptualization of locus of control. Miller conceptualized powerlessness as being "situationally determined" (p. 53). That is, powerlessness is dependent upon the situation the individual is in, not the personal characteristics that the individual brings to the situation. Implicit in this view is the idea that powerlessness is a state rather than a trait characteristic.

Powerlessness affects an individual's state of health and vice versa. Miller (1992) noted observations of individuals in the state of powerlessness "whose physical condition plunged downward despite strict adherence to prescribed regimens" (p. 51). The consequences of health-related powerlessness include low self-esteem, depression, and hopelessness (Miller, 1992).

Powerlessness has been associated with increased illness and hospitalization (Miller, 1992; Sheppard, 1985; Montemuro et al., 1994). Most health care professionals would agree that the elderly are at risk of encountering health-related powerlessness, because of physical, psychological, and material losses. To date, however, no empirical data have been presented to support this notion.

ESRD affects many aspects of personal control over day-to-day life and dialysis treatment. Several studies examined external-internal locus of control and found that patients with greater internal locus of control adapted better than those who were more externally controlled (Poll & Kaplan- DeNour, 1980; Devins et al., 1984; Eichel, 1986;

Kobasa, 1982). Reid (1984) suggests that persons who live in a situation where external controls dominate learn to compensate by distinguishing areas where they do not. ESRD patients receiving long-term hemodialysis are externally controlled in that they require continuing health care, medical technology, and health maintenance. The conflict between maintaining some independence while being dependent on others for health care can be an important psychological stressor for ESRD patients (Stapleton, 2000).

Spirituality

The nursing literature has begun to highlight spirituality and its importance in health. Researchers investigating spirituality and chronic illness have found spirituality to be a powerful resource for coping with health-related problems. Yates, Beasley, Lalonde, Lewis, and Woods (1981) found that religion acted as an important source of support for many patients. Baldree et al. (1982) assessed the methods of coping used by 35 hemodialysis patients and found that hope, prayer, and trust in God were prominent coping mechanisms.

Spirituality is defined by Reed (1987) as an awareness of one's inner self and a sense of connection to a higher being, nature, others, and to some purpose greater than oneself. Spirituality is broader in its domain than religious coping but often in the literature the terms are used interchangeably. Other chronic conditions in which patients have been found to have high levels of spirituality are osteoarthritis (Miller, 1983; Castellaw, Wicks, & Martin, 1999; Martin, 1996), multiple sclerosis (Mohr, Dick, Penn, Boudewyn, Likosky, & Godwin, 1991), cancer (Fehring, Miller, & Shaw, 1997; Kaczorowski, 1989; Mickley & Belcher, 1992, and HIV infection (Coleman &

Holzemer, 1999; O'Neill & Kenny, 1998; Relf, 1997; Tuck, McCain, & Elswick, 2001). Further, Matthews (1997) notes that religion and spirituality are resources beneficial to both physical and emotional health and should be included with traditional medical treatment. Fryback and Reinert (1999) reported that individuals with potentially life-threatening diseases, such as cancer or HIV who found meaning in their disease perceived improved quality of life after the diagnosis.

Past research has described interesting sociodemographic differences in relation to spirituality and chronic illnesses. More specifically, research has documented that women with chronic illnesses cope better and deal more effectively than men (Lauver, 2000) and that they have better spiritual well-being (Fernsler, Klemm, & Miller, 1999). Other studies have shown that regardless of health status, older individuals have higher levels of spirituality than younger persons (Gioiella, Berkman, & Robinson, 1998; Moberg, 1965). In a study of 609 older adults, being Black and female was associated with higher levels of religiosity and higher frequency of prayer (Mull, Cox, & Sullivan, 1987). This study was validated by other researchers addressing higher levels of participation by Black adults in religious activities (Levin & Taylor, 1993; Newlin, Knafl, & Melkus, 2002). Finally, research has documented that persons with lower socioeconomic status have higher frequency of prayer and perceive religious beliefs to have higher levels of importance than individuals with higher socioeconomic status (Mull et al., 1987). Since the majority of patients on hemodialysis are African-American (USRDS, 2002) who have low socioeconomic status, these findings are especially important to note.

All of these studies support the importance of assessing spirituality and religious coping in individuals with life-altering conditions such as ESRD. It is important for providers to have an awareness of the internal resources utilized by ESRD patients in order to cope with their chronic illness.

Depression

In the psychological literature, there are a variety of positions taken about what constitutes depression. To some writers, there is no working definition at all just a list of symptoms. For the purposes of this study on hemodialysis patients, the focus will be on the cognitive features of depression.

Depression is thought to be the most common psychiatric abnormality in patients with ESRD treated with hemodialysis (Kimmel et al., 2000; Kimmel, Weihs, & Peterson, 1993; Levenson & Glocheski, 1991; Wuerth et al., 2001). Depression can be a response to a loss, and ESRD patients have sustained multiple losses, including loss of role within the family and workplace, renal function, mobility and physical skills, cognitive abilities, and sexual function.

Lowery and Atcherson (1980) reported an 18% prevalence of major depression in a group comprised mostly of White patients beginning home hemodialysis in Iowa. Hinrichsen, Lieberman, and Pollack (1989) found that 17.7% of prevalent in-center hemodialysis patients satisfied criteria for minor depressive disorder, and 6.5% met criteria for a diagnosis of major depression.

Smith, Hong, and Robson (1985) pointed out the dramatic overlap between the symptoms of depression and those of uremia. The potential confounding between uremic

and depressive symptoms makes research with ESRD patients difficult. But no overlap exists between the symptoms of uremia and the thoughts associated with depression: feelings of guilt and worthlessness, preoccupation with death and ideas regarding suicide. Depressive symptoms can be characterized as either somatic or cognitive. Using instruments that measure cognitive symptoms of depression and excluding somatic symptoms would be indicated.

Higher levels of depression in ESRD patients treated with hemodialysis are associated with increased mortality (Kimmel et al., 2000; Lopes et al., 2002). Over the last twenty years, several authors have assessed the relationship between depression and mortality in hemodialysis patients but reached similar conclusions. Ziarnik, Freeman and Sherrard (1977) evaluated 47 in-center hemodialysis patients before they began renal replacement therapy. Because patients who died within one year had higher baseline depression scores than did the survivors, they concluded that depression was an early mortality marker. Wai, Burton, and Richmond (1981) used discriminant analysis techniques to study 241 home dialysis patients and concluded that age, level of serum albumin, stress, and extent of depressive affect were different between survivors and non-survivors at baseline. Burton, Kline, and Lindsey (1986) conducted a study of 167 home hemodialysis patients and demonstrated that in addition to age and depression personality factors differentiated survivors and non-survivors. In a population of 64 in-center and home hemodialysis patients, Schulman, Price, and Spinelli (1989) found that those with higher depression scores had significantly poorer survival rates.

The number of persons with ESRD is growing progressively older. Elderly persons suffering from a chronic illness seem particularly vulnerable to depression (Kennedy, Craven and Roin, 1990; Roberts, Kaplan, Shema, & Strawbridge, 1997). Depression is higher for elders who report any chronic illness than any other elders (Bazargan & Hamm-Baugh, 1995), and it appears that the greater the impairment of physical health, the greater the elder's risk of depression (Badger, 1993).

After reviewing the literature on depression in hemodialysis patients, the definition used in this study on depression will be one that focuses on the cognitive experience. This experience is characterized by an emotional condition characterized by overwhelming feelings of gloom, despair, helplessness, and hopelessness.

Table 1

Conceptual Definitions

The following conceptual definitions will be used of the variables in this study:

Quality of Life	A measure of satisfaction with life that is a cognitive evaluation derived from a comparison of one's aspiration to one's actual achievement.
Functional Health Status	Multidimensional concept that encompasses the actual performance of personal care, household, and social and community activities.
Powerlessness	Personal perception that one's actions cannot significantly affect outcomes.
Spiritual Coping	Religious coping behaviors including trust, faith in God, private prayer, and help and strength from a higher power.
Depression	Emotional condition characterized by overwhelming feelings of gloom, despair, helplessness, and hopelessness.

Application of the Roy Adaptation Model

This study was guided by the Roy Adaptation Model of Nursing (Roy & Andrews, 1999) and the findings in the literature. Roy Adaptation Model proposes that individuals are adaptive systems who constantly interact with a changing internal and external environment. According to the Roy model, the environment is more precisely known as focal, contextual, or residual stimuli. The focal stimulus is “the internal or external stimulus most immediately confronting the person” (Roy & Andrews, p. 8)... Contextual stimuli are all other known stimuli “present in the situation ... that will influence how the person can deal with the focal stimuli” (Roy & Andrews, 1999, p 9). Residual stimuli are defined as internal and external environmental factors whose effects are not known or are unclear in the given situation.

In the proposed study, the focal stimulus is represented by the time in months the older person has been on dialysis. The contextual stimuli include age and income. The residual stimulus is represented by the person’s gender and educational level.

The control processes, as explained by the RAM, are internal processes of the person that evoke behavioral responses (Roy & Andrews, 1999). The mechanisms are defined by the regulator and cognator subsystems. In this study, the regulator and cognator (which is the subsystem that responds automatically through neural, chemical, and endocrine processes) are not studied.

Behavioral responses, according to the RAM, can be observed within four modes of adaptation. The four modes are physical, self-concept, role function, and interdependence. In this study the physical mode is represented by the number of

hospitalizations the person has had in the last year. The hospitalization rate and the level of anemia are two outcome measures recommended for improving the quality of life and the quality of care of patients with ESRD (Kinchen & Powe, 2001).

The self-concept mode is represented by the variables of spiritual coping and mental health (depression). The role-function mode is represented by the personal care activities, household activities, and social and community activities that make up the total functioning of the person. The interdependence mode is represented by the sense of power or powerlessness the person feels in relation to their illness. Power can be seen as a social exchange relationship in which power is inherently asymmetrical as in the relationship between the patient and health care providers.

The outcome of the RAM is adaptation. In this study, the outcome of interest was quality of life. This study examined the relationships in a proposed model between powerlessness, functional health status, spiritual coping, and depression to the quality of life of older hemodialysis patients using the RAM as a guide. The conceptual-theoretical structure is shown in Table 2.

Table 2

Conceptual – Theoretical Structure

Stimuli	Behaviors	Outcome
Focal Stimulus:	Physical mode:	Quality of Life
Time on Dialysis	Number of hospitalizations	
Contextual stimuli:	Self-concept:	
Age and Income	Depression Spiritual coping	
Residual stimulus:	Role Function:	
Gender and Education	Personal care activities Household activities Social and Community activities	
	Interdependence:	
	Powerlessness	

Summary

Understanding the relationships between QOL and other variables is an important research goal. Through discerning the variables that affect QOL, interventions to improve QOL may be identified and prioritized. The complex interrelationships among the physical and psychosocial variables related to living with ESRD and their resulting influence on the QOL of elderly hemodialysis patients have not been well examined.

CHAPTER III

METHODOLOGY

To examine how physical and psychosocial factors contribute to the perceived quality of life of older hemodialysis patients, a causal modeling design was used. A design of this type involves the development of a hypothesized causal explanation of a phenomenon and the testing of that explanation through statistical procedures. (Polit & Hungler, 1999). Path analysis was used to examine the interrelationships and the contributors to the proposed model. The dependent variable in this study was quality of life and the paths by which functional health status, powerlessness, depression, spiritual coping and demographic data contribute to quality of life are explained.

Design

Path analysis was used to examine the proposed effects of the contextual stimuli (age and income), focal stimulus (time on dialysis), residual stimuli (gender and education), physical mode (number of hospitalizations in the last year), self-concept mode (mental health and religious coping), role function (total functioning), interdependence mode (powerlessness), and quality of life.

Setting

Data collection occurred at two free-standing outpatient dialysis clinics owned by the same not-for-profit healthcare system that serves a seven county area in west central Georgia and east central Alabama. The centers have the same medical and nursing Directors but have different nursing staffs.

Sample

The target population included older individuals with a medical diagnosis of chronic renal failure or end-stage renal disease (ESRD) who receive hemodialysis treatment. For the proposed study, participants included in the sample were required to be 65 years of age or older, able to understand the English language, cognitively intact, and willing and able to complete the study packet. Participants also had been treated with hemodialysis for a period greater than six months. McClellan et al., (1991) found that patients who had been on dialysis less than six months frequently experience uremia-induced debility. This debility could potentially compromise the measure of functional health status. Further, because people with ESRD are usually on dialysis for several years, the initial response to dialysis treatment would likely be different than what it would be over time.

Elderly hemodialysis patients willing to participate in the study who met the study criteria were eligible to become part of the sample. The patient availability in this relatively small, select population and time limits for completing the study dictated that the sample was one of convenience.

Power analysis was used to determine sample size. The conventions for power (.80) and significance level (.05) and an effect size that was estimated from a previous study of quality of life of hemodialysis patients ($r = .31$) (Kutner et al., 2000) was used to guide sample size. The effect size is the degree to which the phenomenon under study is thought to exist and is measurable in the population (Cohen, 1988). The estimated value of the effect size here is actually the expected population correlation coefficient. Using

Polit and Hungler's (1999) sample size table for the estimated population value when the Pearson's r is used with an alpha of .05 and power of .80 yields a sample size goal of 88 participants.

Protection of Human Subjects

Human assurance approval was sought from the Georgia State University IRB prior to data collection. Permission was sought from the dialysis clinic's medical and nursing Directors. The proposal was also submitted for approval to the Institutional Review Board of the healthcare system.

Participant consent was obtained using a written consent form. The consent form briefly outlined a description of the study and expectations of the participants. To ensure that the consent form was understood and read in its entirety, the investigator reviewed the contents with each participant. It was made clear to each participant that participation was strictly voluntary and that they retained the option to withdraw at any time. To ensure confidentiality, a coding system was used to identify each data collection packet. The coded consent forms were kept in a locked filing cabinet in the investigator's possession. Identifying materials linking patient codes to individual names were destroyed within two years after the completion of the study. Data entered into the computer for analysis contained only patient codes as identifiers.

Instruments

The variables that were measured in this study include quality of life, depression, powerlessness, functional health status, spiritual coping, and demographic characteristics.

The following sections contain information regarding the instruments that were used to measure each study variable.

Demographic Questionnaire

Data were collected on a number of socio-demographic characteristics on a questionnaire developed by the investigator. Information was collected on age, gender, ethnicity, marital status, income, educational background, living arrangements, and length of time on dialysis. Clinical and laboratory data including albumin, hemoglobin, hematocrit, etiology of renal failure, and number of hospitalizations in the past year was also collected.

Quality of Life

Neugarten, Havighurst, and Tobin (1961) developed two indices for measuring life satisfaction in older persons, the Life Satisfaction-A (LSI-A) and the Life Satisfaction-Z (LSI-Z). These indices help identify those who are successfully aging as well as those who may be facing difficulties due to illness or other factors. The original instrument, the LSI-A, contains 36 questions and the shorter LSI-Z has 13 items. For the purposes of this study the LSI-Z will be used. The LSI-Z has been found to have good reliability and validity in older individuals (Wood, Wylie, & Sheafor 1969; Kritz-Silverstein, Wingard, & Barrett-Connor, 2002). The items are related to different domains including resolution and fortitude, congruence between desired and achieved goals, positive self-concept and mood tone. The LSI-Z is designed to be used by interview or it may be administered as a self-report instrument in oral or written form.

The LSI-Z is scored by assigning one point to each item that is ‘correctly’ checked and then summing the ‘correct’ scores. The scaling of the items is ‘agree’, ‘disagree’ or ‘not sure’. A correct score is ‘agree’ on items 1, 2, 4, 6, 8, 9, 11, 12, 13, 14, and 17. Other items are correct if the respondent answers ‘disagree’. The mean score on the original LSI-A instrument was 12.4; however that instrument included two more items than the current LSI-Z.

Content validity was assessed through repeated interviews with people aged 50-90 years about life pattern, attitudes, values, daily activities, social interaction, and other concerns. (Wood et al., 1969). Construct validity has been demonstrated through correlations between the LSI-A and a Life Satisfaction Rating Scale and between the LSI-Z and a Life Satisfaction Rating Scale (Wood et al., 1969).

Center for Epidemiological Studies Depression Scale (CES-D)

The CES-D Scale is a 20-item self-report scale used to measure general depressive symptomatology currently being experienced. The instrument has been widely used in research on community dwelling populations with depression including the elderly (Husaini et al., 1980; Krause, 1986; Pruncho et al., 1990). The scale consists of items rated on a four-point Likert-type scale. Item responses included 0 or “rarely or none of the time”, 1 or “some or little of the time”, 2 or “a lot of the time”, and 3 or “most or all of the time”. Total scores range from 0 to 60. Higher scores on the scale indicate greater depression. A score of 16 or higher has been suggested as reflecting a level of depression associated with a depressive disorder. However, a score of 20 is recommended as the appropriate score for identifying depressive symptomatology in

older persons (Robinson, 1989). The instruments utility as a screening tool has been well documented through validation with clinical ratings of depression (Hertzog, Van Alstine, Usala, Hultsch, & Dixon, 1990). Estimates of internal consistency of the CES-D Scale have been reported with coefficient alpha .90 and the Spearman-Brown split halves method of .85 (Kutner et al., 2000).

Inventory of Functional Status-Dialysis (IFS-D)

The Inventory of Functional Status-Dialysis (IFS-D) was used to measure functional status in this study. The IFS-D is a 23-item, disease specific paper and pencil questionnaire designed to measure the actual performance of personal care activities, household activities, and social and community activities in chronic in-center hemodialysis patients (Thomas-Hawkins et al., 1998). The instrument includes three subscales: the 5-item Personal care activities, the 9-item Household activities, and the 9-item Social and community activities subscale. Participants are asked to indicate whether they have performed each activity within the past 24 hours, using a dichotomous rating scale of 1 for no and 2 for Yes. A “never did” code, which is excluded from score calculations, is used for items not engaged in by the individual even before the diagnosis of ESRD and initiation of hemodialysis. Inasmuch as all IFS-D items may not have been engaged in by every individual as part of his or her usual life style, a mean is used as the score for each relevant subscale and for the total IFS-D. The possible range of scores is 1.00 to 2.00 for each subscale and the total IFS-D. On this scale the higher the score, the greater the level of functional status.

The basis of content validity of the IFS-D was the selection of items that represented function for dialysis patients as well as judgment of the adequacy of those items by a panel of in-center hemodialysis patients. IFS-D items were drawn from the Comprehensive Inventory of Functioning developed by Fawcett & Tulman (1996), as well as clinical observations and suggestions from hemodialysis patients. The final content validity average congruency score for the IFS-D is an acceptable 90%. Construct validity was further examined by assessing correlations between the IFS-D and two generic measures that have been used with hemodialysis patients: the Karnofsky Performance Status Scale (KPS) and the Medical Outcomes Study Short-form 36 Health Survey (SF-36). Correlations between the IFS-D subscales, the KPS, and the SF-36 subscales ranged from .06 to .63. The relatively low magnitude of these correlations further supported the construct validity of the IFS-D and indicated that the IFS-D measures aspects of functioning distinct from the KPS and SF-36 subscales.

Initial reliability of the IFS-D was established in a sample of 175 in-center hemodialysis patients. The Cronbach's alpha reliability coefficient was .86 for the total IFS-D, .73 for the Personal care subscale, .82 for the Household subscale, and .71 for the Social and Community subscale. Bivariate correlations of the subscale scores yielded coefficients ranging from .28 to .53, suggesting that the subscales are relatively independent and that each measures a distinct dimension of functional status (Thomas-Hawkins, Fawcett & Tulman, 1998).

The IFS-D was also used to measure social roles in this study. In the IFS-D, the performance of primary role behaviors is represented by the dimension of personal care

activities and the performance of secondary role behaviors is represented by the dimension of household activities. Performance of tertiary role behaviors is represented by the dimension of social and community activities in keeping with the conceptual definition of social roles for this study. These role behaviors include such activities as participation in volunteer and religious organizations, socializing with friends and family, and taking a vacation. In summary, the IFS-D facilitates assessment of ESRD patients' role function response to external or internal stimuli (e.g., hemodialysis and ESRD).

Religious Coping (RCOPE)

Pargament and Nielson (1997) developed a comprehensive measure of religious-spiritual coping called RCOPE. This measure is designed to be theoretically based, comprehensive and provide for negative as well as the positive aspects of religious-spiritual coping. There are 5-item and 3-item versions of the RCOPE that assess 17 religious-spiritual coping behaviors. These coping methods include benevolent religious appraisals, religious forgiving, spiritual discontent, religious helping, the search for spiritual connection, and anger at God. The scales have been shown to correlate with a variety of measures of stress-related outcomes including physical and mental health and spiritual outcomes (Pargament, Smith, Koenig, & Perez, 1999; Rogers, Poey, Reger, Tepper, & Coleman, 2002).

Pargament, Smith, Koenig and Perez (1998) developed a shorter scale (Brief RCOPE) by selecting 21 items from the RCOPE dimensions. The tool was administered to a sample of family, friends, and acquaintances of victims of the Oklahoma City bombing. Factor analysis yielded two factors: a positive/spiritual coping factor that

reflects benevolent religious involvement and a negative factor that reflects religious struggle. These subscales, positive and negative, have been found to be internally consistent and evidence has been found of criterion-related validity using measures of stress-related growth, post-traumatic stress disorder symptoms, callousness to others, and religious outcomes (Pargament, 1999).

There are two forms of the Brief RCOPE. These forms are situational or dispositional. Whether to use the situational or the dispositional forms of the religious-spiritual coping measure depends on the purpose of the survey. If the purpose is to assess individuals facing a particular life stressor, then the situation-specific form is most appropriate. If the focus is on coping with health issues then dispositional form is best, and this will be the form used in this study. The two subscales of the Brief RCOPE provide for the examination of both the positive and negative effects of religion-spirituality. The estimated time of completion of the Brief RCOPE is 90 seconds to 2 minutes. There are five questions contained in each subscale. The questions are answered using a 4-point scale with 1 being 'a great deal' and 4 being 'not at all'.

Health-Related Powerlessness Scale (HRPS)

The Health-Related Powerlessness Scale (HRPS) was developed for use with non-institutionalized elderly persons. The HRPS is an 11-item measure that is made up of eleven statements that participants mark with a 1 for agree or 0 for disagree. The scores range between 11 and 55. The higher the score the more powerless the person perceives himself.

Content validity for the scale was determined through review by 10 geriatric nursing specialists. The content validity index was .88. Internal consistency reliability was performed by comparing each item of the HRPS with all other items by using coefficient alpha comparison, which was .74. Construct validity was tested by assessing the relationship between the HRPS, Dean's Powerlessness Scale (.36), Self-Assessment Scale (-.21) and the Beck Depression Inventory (.39) (Thames, 1995). In order to determine whether or not the HRPS measured a different facet of powerlessness from the Dean's Powerlessness, both instruments were subjected to factor analysis by varimax rotation. HRPS loaded different factors indicating that two distinct facets of powerlessness were being measured. These results establish divergent validity.

Data Collection

Once health system administration and IRB approvals were obtained, potential participants were approached individually and had the purpose of the study explained to them. Once they agreed, the parameters of informed consent were explained, and they were asked to sign the consent form. Two copies of the consent form were included in the packet. One copy was signed by the participant and returned to the investigator. The other copy was made available to the participant as a personal copy. The setting for the administration of the selected instruments and demographic questionnaire was at the patient's chair-side during the dialysis procedure or while waiting to go on the dialysis machine. While the original plan was for the participants to be able to complete the forms after the dialysis treatment by taking them home, it became apparent after the first two interviews that it was necessary for all the instruments to be read aloud to the

participants. This became necessary not only because of poor eyesight but also because the participants could not write during the dialysis treatment due to forearm shunts. It was expected that all items could be completed in thirty minutes, but participants were allowed as much time as they needed.

The participants were given a packet containing all the study instruments and the consent form. Each participant completed all study instruments and a demographic questionnaire. The dialysis patients' primary cause of renal failure, dialysis start-date, and date of birth was verified with information from the dialysis facility. The patients' most recent hematocrit level was obtained along with the number of hospitalizations during the past 12 months. These measures were used as a means of determining how well the individual patient is managing their disease. Studies have shown that anemia is correlated with clinical outcomes (Kinchen & Powe, 2001). Ma, Ebben, and Xia (1999) found an increased risk of death in ESRD patients who had hematocrits less than 30%. Those with hematocrits between 30 and 33% had much better outcomes. Hospitalization rate is often viewed as a good measure of morbidity (Kinchen & Powe, 2001).

Because the ESRD patient is often visually impaired, the investigator provided large type print versions of the instruments. During data collection the research investigator was available to answer any questions. When the participant completed all the forms, they replaced them in a large envelop and returned them to the investigator.

Data Analysis

Path analysis was used to construct a model identifying significant predictors of the major dependent variable (QOL). Bivariate correlation measures were performed to

determine what relationships, if any, exist between the independent variables. An alpha level of .05 was used for all statistical tests in this study.

A model was developed from the significant relationships among the study variables and their contribution to quality of life. Path analysis was used to test the proposed model. Path analysis enhances the ability to analyze the complex, interwoven relationships that exist when psychosocial variables are being assessed. The rationale for selecting this method is to achieve the most parsimonious path model by eliminating those paths that failed to make a significant contribution to a prediction of what constitutes the quality of life of older hemodialysis patients.

Plan for Data Management

After verifying the statistical assumptions for path analysis, the direct and indirect effects of the study variables on the dependent variable were identified. The exploratory path model of quality of life of elderly ESRD patients is presented in Figure 2 and was used as a blueprint for the data analysis.

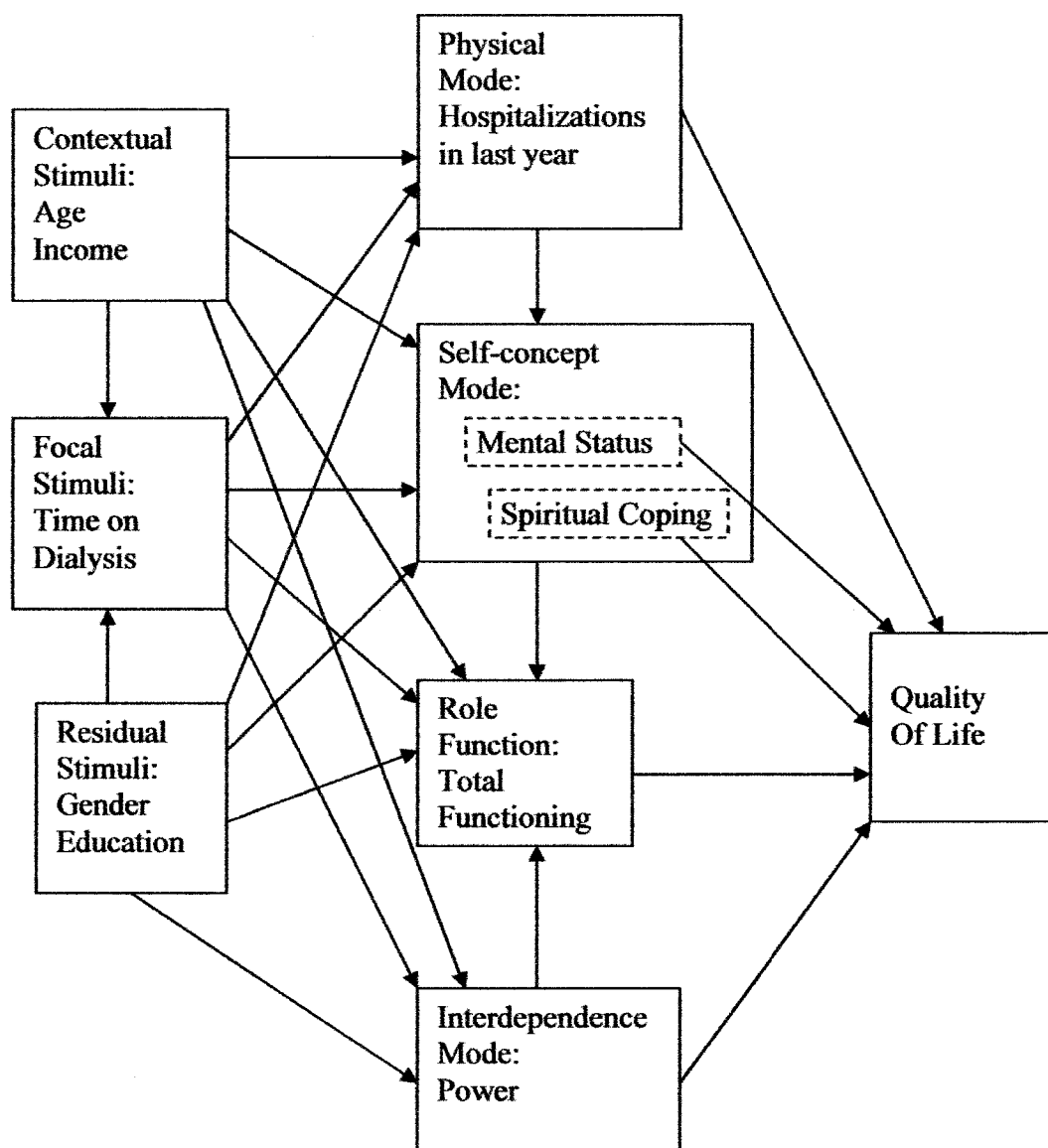


Figure 2: Proposed Path QOL in Elderly Hemodialysis Patients

Chapter IV

RESULTS

This chapter contains the results of the analysis of this research study. The sample characteristics are presented first, followed by a discussion of the concepts used in the measurement of the model. Next, data analysis and the path model are examined in detail. The chapter concludes with presentation of the final path model.

Sample Characteristics

The 79 participants in this study are described in Table 3. The average age of the participants was 71.9 years old. The minimum age was 65 and the oldest participant was 86. Of the 79 participants, 57% were male and 43% were female. The mean educational level was 9.8 years in school. The race of the sample was 73.4% African American and 27% Caucasian. Of the participants, 32 were married (40.5%), 31 were unmarried (39.2%) and 15 (19%) were widowed. The most common income level (56%) was \$10,000 to \$20,000.

Table 3

Demographic Characteristics

Characteristic	N	Percent
Age (Range = 65 – 86, Mean = 71.9)	79	
Gender		
Male	45	57%
Female	34	43%
Race		
African American	58	73%
Caucasian	21	27%
Educational Level		
5th – 8 th Grade	21	27%
9th – 12th grade	54	68%
1 to 2 years College	4	5%
Marital Status		
Not Married	32	41%
Married	31	39%
Divorced	1	1%
Widowed	15	19%
Income		
Less than \$10,000	11	14%
\$10,000 to \$30,000	58	73%
\$30,001 to \$60,000	9	11%
\$over \$60,000	1	1%
Religious Preference		
Baptist	41	52%
Methodist	22	28%
AME	15	19%
Catholic	1	1%

Descriptive Characteristics

The clinical characteristics of the participants are represented in Table 4. The average time on hemodialysis was 38 months with a range of from 8 months to 108 months (9 years). The major causes of end-stage renal disease for this sample were diabetes (49%; N= 39) and hypertension (41.8%; N = 33). The 79 participants were reasonably well managed in the control of their disease as shown by the number of times they had to be hospitalized in the past year. Twenty-eight (35%) had not been in the hospital at all in the last year and 24 (30.4%) had only been hospitalized once. The most recent laboratory values including albumin level, hemoglobin, and hematocrit were obtained at the time of data collection. The mean hemoglobin was 11.3% (range 5.3 to 13.5), the mean hematocrit was 35% (range 16.1 to 42.6) and the mean albumin level was 3.9% (range 3.0 to 4.5).

Table 4

Clinical Characteristics

Data	N	Percent
Etiology of Disease		
Diabetes	39	49%
Hypertension	33	42%
Glomerulonephritis	3	4%
Congestive Heart Failure	3	4%
Other	1	1%
Laboratory values		
Hemoglobin		
Value: 5.0 – 10.0	13	16%
Value: 10.1 – 12.0	42	53%
Value: 12.1 – 13.5	24	31%
Normal: Male: 13.5 – 18	N/A	
Female: 12 - 16		
Hematocrit		
Value: 16.0 – 34.0	22	28%
Value: 34.1 – 38.0	41	52%
Value: 38.1 – 43.0	16	20%
Normal: Males: 40 – 54	N/A	
Females: 36 - 46		
Albumin		
Value: 3.0 – 3.5	14	18%
Value: 3.6 – 4.0	38	48%
Value: 4.1 – 4.5	27	34%
Normal: 3.5 – 5.0	N/A	

Table 5 below shows the range, means, and standard deviations for all path variables. The self-concept mode is represented by two variables, mental health and spiritual coping. This sample scored low on the mental health scale meaning there was

little depression. The sample scored high on the spiritual coping scale. The sample also scored high in total functioning with the highest scores being on the personal care subscale. The interdependence mode represented by powerlessness showed that this sample was in the middle range of the powerlessness scale. The quality of life score (11.23 out of a possible 18) was slightly above the midrange for scores (9).

Table 5

Descriptive Statistics for Variables in the Model

Variable	Possible Range	Obtained Range	M	(SD)
Contextual Stimuli				
Age	> 65	65- 86	71.91	(5.14)
Income		1-7	2.37	(1.08)
Focal Stimulus				
Time on Dialysis	NA	8-08	38.4	(22.2)
Residual Stimuli				
Gender	NA			
Education	5-14	5 - 14	9.81	(2.30)
Physical Mode				
No.of Hosp.	NA	0 - 7	1.33	(1.53)
Self-concept Mode				
Mental health	0 - 60	0-52	9.28	(9.53)
Spiritual coping	11- 44	30-45	41.21	(3.36)
Role Function Mode				
Total Functioning	0-44	25-44	33.77	(5.10)
Personal Care	0-10	5-10	9.17	(0.71)
Household	0-18	9-18	13.42	(2.92)
Social & Community	0-16	8-16	11.19	(2.07)
Interdependence Mode				
Powerlessness	11-55	15-39	25.32	(4.69)
Quality of Life	0-18	4-18	11.23	(3.39)

Path Analysis

The study data contained 79 cases. The assumptions of normal distribution, homoscedasticity, and linear relationships were met for the multiple regressions in the study. Assumptions unique to path analysis were verified. There was a one-way flow of causation in the model making it recursive. All variables except gender were measured on an ordinal level.

Path Analysis and Reduced Model

Five endogenous variables (Physical mode, Self-concept mode, Role function, Interdependence mode, and Quality of life) and three exogenous variables (Contextual, Focal, and Residual stimuli) were included in the proposed exploratory model. First, bivariate correlations were examined to identify significant variables. Next, a multiple regression analysis of all variables predicted by the proposed model was done. Multiple regressions were performed again with only the significant variables identified in the first regression entered. Last, the final model with all significant path coefficients is presented with the theorized, directional relationships given.

Assessing Contributors to the Focal Stimulus

Bivariate relationships between the contextual, focal, and residual stimuli and the adaptive modes are shown in Table 6. Age and time on dialysis were significantly related as was education and income, and education and time on dialysis.

An initial multiple regression was performed with time on dialysis (the focal stimulus) as the dependent variable and age, income, gender, and education as the independent variables. Education was the only significant contributor to the focal

stimulus. A second and final multiple regression was done with just education entered as an independent variable. The adjusted R^2 was .11 ($p=.002$) and education remained a significant contributor ($\beta = -.350$).

Assessing Contributors to the Adaptive Modes

According to the original model, the contextual, focal, and residual stimuli should have significant bivariate relationships to all four adaptive modes. As shown in Table 6, none of the five variables representing the three stimuli (contextual, focal, and residual) had a significant relationship to any of the adaptive modes (physical, self-concept, role function, interdependence).

Table 6

Bivariate Correlation of Contextual, Focal, and Residual Stimuli to Adaptive Modes

	Age	Income	Time on Dialysis	Gender	Education	Physical Mode	Self- Concept Mode (Mental Health)	Self- Concept Mode (Spiritual Coping)	Role Function Mode	Independence Mode
Age										
Income	-0.09									
Time	0.20*	-0.14								
Gender	0.005	-0.11	0.09							
Education	-0.40	0.55**	0.35**	0.03						
PM	0.04	-0.15	0.1	0.08	-0.11					
SC – MH	-0.18	-0.04	0.1	0.01	-0.008	0.14				
SC – SC	-0.14	-0.11	-0.003	0.11	0.03	0.13	0.18			
RFM	0.21	0.28**	-0.03	0.04	-0.01	-0.14	-0.26**	-0.23*		
IM	-0.05	-0.25*	0.05	-0.07	-0.11	0.01	0.19*	-0.03	-0.18**	

* $P \leq 0.05$

** $p \leq 0.01$

Next, the initial regression analysis was performed for each of the adaptive modes as dependent variables in turn with variables predicted by the path model (Figure 2) as independent variables. The results of the regression analyses are presented in Table 7.

Table 7

Initial Multiple Regression Analyses Adaptive Modes

Outcome Variable	Predictor Variables	β	p	Adj.R ²
Physical Mode				
	Age	.00	.38	
	Income	-.14	.08	
	Time on Dialysis	.07	.18	
	Gender	.06	.24	
	Education	-.01	.17	
			.75	-.03
Self-Concept Mode				
Mental Health	Age	-.23	.08	
	Income	-.00	.98	
	Time on Dialysis	.12	.35	
	Gender	.01	.95	
	Education	-.05	.77	
	No. of Hosp.	.13	.27	
			.50	-.01
Spiritual Coping	Age	-.13	.31	
	Income	-.12	.40	
	Time on Dialysis	.01	.96	
	Gender	.08	.49	
	Education	.05	.74	
	No. of Hosp.	.12	.33	
			.65	-.02
Role Function Mode				
	Age	.10	.35	
	Income	.28	.02*	
	Time on Dialysis	-.05	.64	
	Gender	.07	.48	
	Education	-.19	.16	
	Self- Concept –MH	-.13	.22	
	Self-concept – SP	-.18	.08	
	Interdependence	-.41	.00*	
			.00*	.31

(Table 7 continues)

(Table 7 continues)

Initial Multiple Regression Analyses for the Adaptive Modes

Outcome Variable	Predictor Variables	β	p	Adj.R ²
Interdependence Mode	Age	-.08	.51	
	Income	-.23	.10	
	Time on Dialysis	.04	.75	
	Gender	-.10	.40	
	Education	.00	.99	
			.43	.00

* $p \leq .05$

Table 5 shows that models could not be constructed using multiple regression for the physical mode, the self-concept/mental health mode, the self-concept/spiritual coping mode, or the interdependence mode. The regression for role function as the dependent variable was significant.

These results indicated that only one final multiple regression should be performed, one for role function as the dependent variable with only the significant independent variables of income and interdependence as predictors. The results of this regression are shown in Table 8.

Table 8

Final Multiple Regression Analysis for the Adaptive Modes

Outcome Variable	Predictor Variables	β	p	Adj. R ²
Role function Mode	Income	.18	.07	
	Interdependence	-.44	.00*	
			.00*	.25

* $p \leq .05$ *Assessing Contributors to Quality of Life*

The relationships between the four adaptive modes and quality of life were examined. According to the original model, the four adaptive modes should all be related to quality of life. It was also reasonable to expect the four modes would relate to each other. It was proposed that the physical mode would influence the self-concept mode and the self-concept mode would influence the role function mode. Those who were more often in the hospital (physical mode) were expected to be more likely to be depressed (self-concept/mental health). People who were more depressed were expected to have lower physical function and be less able to perform various roles (role function). It was also predicted that the interdependence mode would relate to the role function mode because individuals who felt more powerless in relation to their chronic illness were expected to have poorer functioning.

The bivariate relationships between the four adaptive modes and quality of life were examined. As shown in Table 9, the role function mode, interdependence mode, and the mental health variable of the self-concept mode all had significant bivariate relationships to quality of life. The physical mode, represented by the number of hospitalizations in the last year, was not significant to either quality of life or the other adaptive modes.

Table 9

Bivariate Correlation of Four Adaptive Modes with Quality of Life

Variables	QOL	Physical Mode	Self-Concept MH	Self-Concept SC	Role Func.	Interdp.
Quality of Life						
Physical Mode	-.01					
Self-concept Mode (Mental Health)	-.56**	.14				
Self-concept Mode (Spiritual Coping)	-.04	.13	.18			
Role Function Mode	.70**	-.14	-.26**	-.23*		
Interdependence	-.54**	.01	.19	-.03	-.48**	

* $p \leq 0.05$

** $p \leq 0.01$

First, the five variables representing the four adaptive modes were entered into the multiple regression. As shown in Table 10, quality of life was significantly influenced by the two variables making up the self-concept mode (mental health and spiritual coping),

the role-function mode, and the interdependence mode. The physical mode was not a significant predictor of quality of life.

Table 10

Multiple Regression Analysis of the Four Adaptive Modes with Quality of Life

Outcome Variable	Predictor Variables	β	p	Adj.R ²
Quality of Life	Physical Mode	.02	.82	
	Self-Concept			
	Mental Health	-.40	.00*	
	Spiritual Coping	.15	.04*	
	Role Function	.52	.00*	
	Interdependence	-.21	.01*	
			.00*	.68

* $p \leq 0.05$

A second multiple regression analysis was performed with only the four significant variables of the three adaptive modes included as independent variables.

These results are shown in Table 11.

Table 11

Multiple Regression Analysis of Three remaining Adaptive Modes to Quality of Life

Outcome Variable	Predictor Variables	β	p	Adj.R ²
Quality of Life	Self-Concept			
	Mental Health	-.40	.00*	
	Spiritual Coping	.15	.03*	
	Role Function	.52	.00*	
	Interdependence	-.21	.01*	
			.00*	.68

* $p \leq 0.05$

As shown in Table 11, the self-concept, role function, and interdependence modes jointly explained 68% of the variance in predicting quality of life in this sample (adjusted $R^2=.68$). This suggests that the variables in the multiple regressions for quality of life are strong.

Reduced and Modified Path Model

Paths that were not significant in the exploratory model were deleted. According to this model, two endogenous variables and two exogenous variables remain. The path coefficients in Figure 3 were obtained from the significant standardized betas in the final multiple regressions and are shown below in Table 12.

Table 12

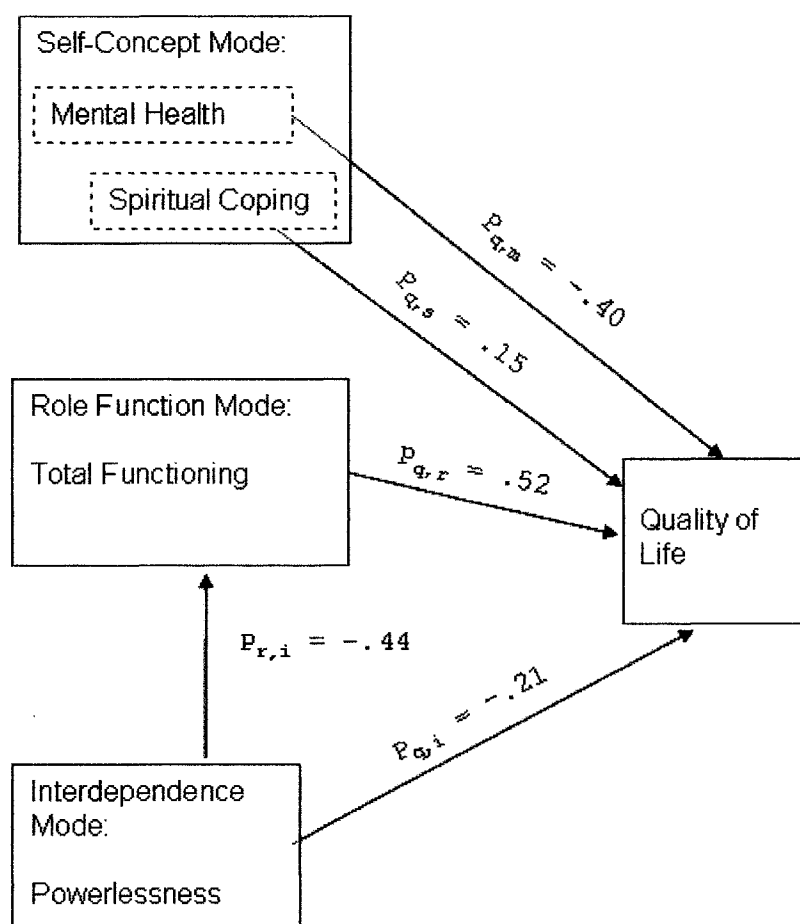
Path Coefficients in the Final Model

Outcome Variable	Predictor Variables	β	p	Adj.R ²
Role Function	Interdependence	-.44	.00*	.25
			.00*	
Quality of Life	Self Concept: Mental Health	-.40	.00*	.68
	Spiritual Coping	.15	.03*	
	Role Function	.52	.00*	
	Interdependence	-.21	.01*	

* $p \leq 0.05$

Figure 3

Final Path Model with Path Coefficients



Chapter V

DISCUSSION

The goal of this study was to examine how physical and psychosocial factors contribute to the perceived quality of life of older hemodialysis patients. The final path model depicted several predictors that influence quality of life in the elderly dialysis patient: total functioning, mental health, spiritual coping and sense of power. An overview of the major findings of this study will be presented in this section as well as discussion of implications for theory development and nursing practice. Study limitations will be addressed as well as recommendations for future research.

Findings

The Sample

Since 1978, the median age at which patients begin ESRD treatment has increased 21%, or from 54 to 65 (USRDS, 2004). Whites have the highest median age of all racial and ethnic groups at 67.9 years, and Blacks the lowest at 59.5 years. Of the 18 ESRD networks in the United States Network #6 (which contains Georgia, North Carolina, and South Carolina) has the largest number of dialysis patients. The mean age of those in the network is 61 years old with whites representing 42.5% and Blacks representing 54.7% of the population in this network. This study's participants were older than the national and network average at 71.9 years. Also, this study's racial mix was heavily African American (73%) with Whites representing only 27%.

Kinchen and Powe (2001) report that anemia is an important part of outcomes measurement in ESRD care. Ma et al. (1999) found that there was increased risk of death

in patients with ESRD with hematocrits between 30 and 33%. While the optimal hematocrit is not known, the United States National Kidney Foundation recommends a hematocrit of 33% and 36% for epoetin therapy. The majority (52%) of the participants in this study had hematocrits in the range of 34.1% to 38.0% slightly above range recommended.

Nutrition is a key issue in the care of ESRD patients. Studies have shown that low serum albumin levels are associated with poor outcomes including mortality (Owen, Lew & Loi, 1993; Foley, Parfrey, & Harnett, 1996). The National Kidney Foundation's Nutrition Work Group (2001) identified stable albumin levels as an important measure of nutritional status in dialysis patients. The albumin levels for 82% of this group were within the normal range of 3.5 to 5.0.

Patient demographic data of the USRDS Network # 6 reports that 43.7% have diabetes as the leading cause of ESRD. In this study, the leading cause was also diabetes (49%) with hypertension a close second (42%).

Overall, the sample had slightly more Blacks and was older than the national sample. The clinical data of the sample showed that the participants had hematocrits slightly above recommended values and albumin levels within the normal range. As is true with the majority of end-stage renal disease patients, this sample had diabetes as the leading cause of their renal failure.

The Final Model

This study indicated that the self-concept mode, role function mode, and interdependence mode explained 68% of the variance in the quality of life of elderly hemodialysis patients. The fourth mode, physical mode, had no effect on quality of life or the other adaptive modes. The role function mode had the greatest effect on quality of life of this sample. Those who had better functioning had higher quality of life scores.

Contextual, Focal, and Residual Stimuli

Of all the variables that represented the contextual, focal, and residual stimuli, none were significant contributors to the four adaptive modes. The contextual stimuli contained the variables of age and income. Age had a slight bivariate correlation relationship to both time on dialysis and educational level. These findings are consistent in that the older the person the longer they had been on dialysis. In this sample, older persons had lower education levels than those who were younger as might be expected. The residual stimulus variable of education influenced the focal stimulus (time on dialysis) however, there were no significant paths from any of the three stimuli variables to the adapt modes.

Adaptive Modes

Physical mode. The physical mode was represented in this study by the number of hospitalizations in the past year. The physical mode had no influence on the other adaptive modes or the perceived quality of life. This group of participants was managing their disease well as evidenced by their nutritional status (albumin levels) and anemia (hemoglobin and hematocrit). Thus, the number of hospitalizations was very low in this

sample. The dialysis units utilized in this study had a multidisciplinary approach to handling patient issues, both physical and psychosocial. As the physical mode was insignificant in this study, this path was eliminated from the final model.

Self-concept mode. The self-concept mode of the RAM focuses on psychological and spiritual dimensions of behavior (Roy & Andrews, 1999). The self-concept mode in this study was represented by two variables that were treated separately. The first variable, mental status was defined in this study as depression. Kimmel et al. (2000) in a study on depression and survival of hemodialysis patients found that older African American dialysis patients were at increased risk for depression. Participants in this study had very low levels of depression. Their level of depression had an inverse relationship to quality of life and total functioning ability as would be expected.

The second variable that made up the self-concept mode of this study was spiritual coping. The association between religion and spirituality and clinical outcomes is increasingly appreciated in the literature (Patel, et al., 2002). Religiosity and spirituality may have roles as coping mechanisms for chronic illness. Cross-sectional and longitudinal studies have shown that religious and spiritual coping are associated with less depression during illness (Kennedy et al., 1996; Koenig, Cohen, & Blazer, 1992; Patel et al., 2002). Koenig et al. (1992) showed that religious involvement is associated with greater likelihood of remission and a rapid remission from depression. Religious involvement and spiritual well-being also have been associated with greater levels of health-related quality of life (Riley et al., 1998; Cotton et al., 1999). This relationship has shown to hold true despite declines in physical functioning (Brady et al., 1999). Other

studies also have shown that religious coping lessens the negative impact of physical illness on functional status (Koenig et al., 1992; Matthews et al., 1998). There was no correlation shown between spiritual coping and depression with this group nor did the variables contribute to the role function mode. In this study, spiritual coping had a direct influence on quality of life.

Role Function mode. Functioning is reported as a particularly important part of ESRD patients' assessment of their quality of life (Kutner & Jassal, 2003; Hawkins et al., 1998). In elderly patients, the comorbidities and age-related changes increase the physical challenges of hemodialysis patients. Improving the function of ESRD patients is becoming increasingly important as a goal of clinical practice. The role function mode was the greatest contributor to quality of life in this study but was also influenced by the interdependence mode. In this study total functioning was measured using the Inventory of Functional Status-Dialysis scale designed to examine functional status in persons who are receiving chronic in-center hemodialysis treatments. The instrument was derived from the role function mode of the Roy's Adaptation Model (RAM) and focuses on the roles the person occupies in society and directs attention to activities associated with primary, secondary, and tertiary roles. Activities associated with primary roles include basic activities of daily living such as bathing, dressing, toileting, and eating. Secondary role activities are associated with intermediate activities of daily living such as housekeeping and use of transportation. The tertiary roles are based on advanced activities of daily living such as participating in hobbies, social groups, vacations, and religious organizations. In this study, the scores on the Inventory of Functional Status-

Dialysis were in the high range. The higher the score on this scale, the better the level of function. The highest scores were associated with the primary roles (activities of daily living) and somewhat lower scores for secondary roles (e.g. household duties). This study's participants scored lower on the tertiary roles (social activities) component which was expected. Dialysis patients in general have a harder time being able to go on vacations and attend social functions because of the need for relatively frequent treatment. This particular group was active in church-related activities especially. The participants in this study, though elderly and many with foot or leg amputations, were able to care for themselves at a surprising rate. The majority of the study participants reported being able to do their own cooking and daily household chores. While participants did quite well on activities of daily living, role performance for housekeeping kinds of activities, social activities tended to be low. The findings in this study support functioning as being an important part of quality of life assessment.

Interdependence mode. The interdependence mode in this study was represented by powerlessness. Power can be considered as part of a social exchange relationship in which power is inherently asymmetrical. This holds true for the relationship between patients and healthcare providers. Since power requires a relationship, one's sense of power is contingent on the other actors in the relationship such as found in the interdependence mode of the RAM. Powerlessness is affected more by the situation the person is in rather than by the personal characteristics of the person. For this reason powerlessness was not considered to be part of the self-concept mode. The Health-related Powerlessness Scale used in this study assessed the extent to which the elderly perceive

that one's actions cannot significantly affect the outcome of a situation (Thames, 1995). In this case, the situation is end-stage renal disease with hemodialysis treatment. The mean scores on the powerlessness scale were in the mid-range so that these participants felt less powerless. The interdependence mode (powerlessness) had indirect and direct inverse effects on quality of life. The indirect effects influenced quality of life through the role function mode. The more powerless the person felt, the lower the quality of life. Powerlessness in this sample had a negative relationship to the role function mode. The more powerless patients felt, the lower the score on total functioning ability. Power in relationship to the healthcare environment and their own health care was not measured in this study, but it is reasonable to believe that these factors contributed to the powerlessness scores.

Quality of life. In quality of life research various concepts are used, for example, quality of life, satisfaction with life and well-being. In this study, quality of life was examined by using an instrument designed to measure life satisfaction in elderly people. Despite technical progress in therapy, some investigators find that hemodialysis patients report health-related quality of life substantially lower than that of the general population (Unruh et al., 2002; Kinchen & Powe, 2001; Kutner, Carenas, & Bower, 1992). Other investigators have found a positive association between advancing age and life satisfaction among patients on dialysis. Kimmel et al. (1995) reported that increasing age correlated with higher life satisfaction scores in predominantly African American, urban dialysis patients. Information in the National Kidney Dialysis and Kidney Transplantation Study (2002) investigated possible age-related differences in quality of

life. Patients greater than 65 years old reported greater functional impairment than younger patients but had higher well-being scores.

Although health may become an increasingly important determinant of quality of life as health deteriorates, other influences, particularly interpersonal relationships, remain vital to individual judgments of life quality even in the presence of chronic illness. This being said, the results of this group of elderly dialysis patients rated total functioning as the most important influence on quality of life. Power had indirect effects on quality of life by influencing total functioning as well as direct effects on quality of life. Lower levels of depression, the use of spiritual coping, and relatively low levels of powerlessness along with higher levels of total functioning as influencing quality of life are supported by the path model in this study.

Implications for Nursing Theory Development

Roy's Adaptation Model (RAM) provided a theoretical framework for the study of predictors of quality of life of elderly hemodialysis patients. This study proposed in the beginning path model that the contextual, focal, and residual stimuli influenced the four adaptive modes. The study findings did not bear this out. The RAM states that the contextual, focal, and residual stimuli influence only the focal stimulus. Robinson (1995), in a study using the RAM that dealt with the grief response of widows, proposed a path from the contextual stimulus to the adaptive modes. In this study, the contextual stimuli (age and income) did not have a significant relationship with the adaptive modes. Only education had a significant relationship to the focal stimulus (time on dialysis).

In Roy's theory, the adaptive modes are represented as overlapping circles in an effort to show the interrelationships between the four modes. Even though in this study the physical mode (number of hospitalizations in the last year) was not shown to be a significant predictor of quality of life and had no relationship to the other modes, the mode may have been insignificant due to the small number of hospitalizations of the participants. There were interrelationships between the role function mode (total functioning), and the interdependence mode (powerlessness). The adaptive modes of Roy's model are where the behaviors that contribute to adaptation are seen. The elderly participants in this study adapted by using spiritual coping behaviors and by carrying out roles important to functioning despite feeling somewhat powerless. These adaptive behaviors led to their overall perception of quality of life.

Implications for Nursing Practice

Since end-stage renal disease has become a geriatric illness, nephrology nurses are challenged to meet the special needs of aging dialysis patients. Patient care will improve as health care providers understand more about elderly dialysis patients' total physical and psychosocial needs. This study shows that the role function mode, represented by total functioning, had the greatest effect on quality of life. The importance of role function to the quality of life of elderly dialysis patients indicates that healthcare professionals need to design interventions with a focus on helping them to maintain physical and social activities. Parkerson and Gutman (2000) in a study of health-related quality of life found that higher levels of physical functioning were the strongest predictor of survival for patients on dialysis. Since this study also shows that a sense of

power influences patients' perception of role function and quality of life, then a part of that care should include empowering the patient to be an active participant in his or her own care. The importance of patients having some control and being equal partners in maintaining their health needs to be recognized by healthcare providers in the dialysis setting. Keeping patients informed and explaining the consequences of their actions regarding their daily lives goes a long way toward improving their health outcomes and thus their quality of life.

Spiritual coping also plays a part in influencing quality of life. Several recent research studies (Welch & Austin, 2001; Patel et al., 2002) found that religious involvement and stronger perceptions about the importance of faith were associated with less depression, fewer negative perceptions about the importance of illness effects, and higher quality of life. Social workers and nephrology nurses need to include interventions in dialysis care that take into consideration the spiritual needs of their patients. This study has shown that for some elderly dialysis patients their ability to adapt to end-stage renal disease is influenced by their religious faith.

Healthcare providers who work with hemodialysis patients must recognize the psychosocial impact of renal disease upon the older patient and put in place psychosocial assessment, intervention, and evaluation to provide complete holistic care.

Limitations

The findings of this study should be interpreted with caution because data were collected at only one time and the sample consisted of participants selected using

convenience sampling. The sample also was limited to one geographic area and both dialysis centers were under the leadership of one medical director.

There is also the possibility that this was an elite sample in that the participants all chose dialysis as a life-sustaining treatment thus they may be more likely to report a good quality of life.

Recommendations for Future Research

Research in determining the quality of life of elderly hemodialysis patients has been fragmented at best. Researchers have sought to define quality of life of the chronically ill by using numerous variables. The literature contains no agreed upon definition of what constitutes quality of life for the elderly who are chronically ill. This study identifies important contributors to quality of life defined as life satisfaction.

Directional effects of the four adaptive modes were suggested by the path analysis in this study. Since path analysis only allows recursive directions, non-recursive relationships among the adaptive modes and quality of life could not be explained in this study. The possibility of non-recursive relationships should be considered in future research studies.

Future research should include replicating this study with a larger sample of participants from more than one geographic area to increase the generalizability of the study findings. Repeating the study with elimination of those variables that did not suggest a significant relationship to the theoretical model and using other statistical methods to identify bi-directional relationships between the adaptive modes and quality of life will also be helpful.

Qualitative studies are needed as well as quantitative. Relatively little is known about the experiences of elderly hemodialysis patients, and qualitative studies are needed to explore the meaning of life quality to them.

Longitudinal studies are also needed to examine changes in quality of life of elderly dialysis patients over time. Little is known about the difference that length of time on dialysis makes regarding overall quality of life.

Findings in this study suggest that elderly dialysis patients perceive their quality of life in a positive way. These findings are encouraging for those who work with dialysis patients. Research efforts that continue to explore a solid understanding of what constitutes quality of life of elderly dialysis patients can help with designing interventions that assist patients to reach their maximum potential.

Summary

Elderly end-stage renal disease patients gain added years to their lifetime by dialysis treatment. These added years can be satisfying ones. Elderly patients as a group often show better psychosocial adjustment to dialysis than do younger patients. However, the limitations in physical functioning that characterize dialysis patients increase with age. The challenge is to identify factors that contribute to improving the functioning and overall quality of life of elderly dialysis patients so that interventions can be targeted by dialysis healthcare providers.

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APPENDIX A

Code Book

Quality of Life

In

Older Hemodialysis Patients

Thank you for participating in this study. Many of the questions may sound the same to you, but please answer each one of them as honestly as you can.

Participant code _____

Researcher initial _____

Demographic Data Sheet

PLEASE ANSWER ALL OF THE FOLLOWING QUESTIONS:

1. Age: _____

2. Male _____ Female _____

3. Marital status:

Not married _____ Separated _____ Married _____

Divorced _____ Widowed _____

4. Last year of schooling completed (Circle):

4 5 6 7 8 9 10 11 12	13 14 15 16	17 18 19 20
Elementary/Jr/Sr High school	College	Graduate school

5. Race:

African American _____ Caucasian _____ Asian _____

Hispanic _____ American Indian _____ Other _____

6. Length of time on dialysis:

_____ Number of years _____ Number of months if less than 1 year

7. Combined household income:

_____ less than \$10,000	_____ \$ 30,001 – 40,000
_____ \$ 10,001 – 20,000	_____ \$ 40,001 – 50,000
_____ \$ 20,001 – 30,000	_____ \$ 50,001 – 60,000
	_____ over \$ 60,000

8. Religious Preference:☐ Baptist☐ Presbyterian☐ Methodist☐ Catholic☐ AME☐ Jewish☐ Episcopal☐ Other _____

Medical Data Form**(For Investigator Use Only)**

Researcher Initials _____

Participant code _____

Date: _____

Etiology of renal failure _____

Most recent Laboratory/Medical Data:

Hemoglobin _____

Hematocrit _____

Albumin _____

Number of hospitalizations in last year and reasons:

Comments:

Functioning

Instructions: Common activities are listed below. Please circle the answer that best describes the activities that you performed in **THE PAST WEEK**. If you never did the activity, even before you started dialysis, please circle the zero in the never did column.

	Never Did	Did activity in past week	
	(circle)	NO (circle)	YES (circle)
1. Bathed or showered myself	0	1	2
2. Dressed myself	0	1	2
3. Used the toilet by myself	0	1	2
4. Took a walk	0	1	2
5. Took care of my hair	0	1	2
6. Washed the dishes	0	1	2
7. Cooked	0	1	2
8. Did light work around the house (for example, make the bed, light home repairs)	0	1	2
9. Did the laundry	0	1	2
10. Did moderate work around the house (for example, vacuum, moderate repairs)	0	1	2
11. Took care of household business (for example, pay the bills, do banking)	0	1	2
12. Did grocery shopping	0	1	2
13. Did shopping for other things	0	1	2
14. Ran errands	0	1	2
15. Attended church services	0	1	2

	Never Did	Did activity in past week	
	(circle)	NO (circle)	YES (circle)
16. Participated in church activities	0	1	2
17. Participated in social clubs	0	1	2
18. Participated in volunteer or service organizations	0	1	2
19. Went out with friends	0	1	2
20. Went out with relatives	0	1	2
21. Visited with friends at home	0	1	2
22. Went to dinner/movies/theater	0	1	2

Religious Feelings

Instructions: Think about how you try to understand and deal with major problems in your life.

	a great deal	quite a bit	somewhat	not at all
23. I think about how my life is part of a larger spiritual force.				
24. I work together with God as partners to get through hard times.				
25. I look to God for strength, support, and guidance in crises.				

	a great deal	quite a bit	somewhat	not at all
26. I try to find the lesson from God in crises.				
27. I confess my sins and ask for God's forgiveness.				
28. I feel that stressful situations are God's way of punishing me for my sins or lack of spirituality.				
29. I wonder whether God has abandoned me.				
30. I try to make sense of the situation and decide what to do without relying on God.				
31. I question whether God really exists.				
32. I express anger at God for letting terrible things happen.				
33. To what extent is your religion involved in understanding or dealing with stressful situations in any way?				

Feelings About Health

Directions: Below are some comments about health. I am interested in knowing how you think about these statements. There are no right or wrong answers. Please check the response that most nearly agrees with how you think. Check only one answer for each statement.

	I agree a great deal	I agree moderately	I am not sure	I agree slightly	I do not agree
34. When I think about my health, in general, I feel I can't help how things, turn out.					
35. I just don't care about how things turn out.					
36. I have difficulty making plans because I don't know if I may run out of energy.					
37. I don't always tell nurses & doctors what I am really feeling because I'm afraid that my care will suffer.					
38. I don't think anything I do will make me better.					

	I agree a great deal	I agree moderately	I am not sure	I agree slightly	I do not agree
39. When I have questions about how to take care of myself, I don't try to find the information I need.					
40. I know that I can't do things as well as I used to because I'm getting old.					
41. I'm not sure what nurses and physicians expect me to do as a patient.					
42. I prefer for nurses and physicians to make decisions about my care instead of me.					
43. When my family and friends help me to stay healthy, I feel guilty.					
44. No matter what I say, the nurses and physicians do what they want.					

Feelings About Mental Health

Directions: Circle the number of the statement that best describes how often you felt or behaved this way - DURING THE PAST WEEK.

	Less than 1 day	1 – 2 days	3 – 4 days	5 – 7 days
45. I was bothered by things that usually don't bother me.	0	1	2	3
46. I didn't feel like eating: my appetite was poor.	0	1	2	3
47. I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
48. I felt that I was just as good as other people.	0	1	2	3
49. I had trouble keeping my mind on what I was doing.	0	1	2	3
50. I felt depressed.	0	1	2	3
51. I felt that everything I did was an effort.	0	1	2	3
52. I felt hopeful about the future.	0	1	2	3
53. I thought my life had been a failure.	0	1	2	3
54. I felt fearful.	0	1	2	3
55. My sleep was restless.	0	1	2	3
56. I was happy.	0	1	2	3
57. I talked less than usual.	0	1	2	3
58. I felt lonely.	0	1	2	3
59. People were unfriendly.	0	1	2	3
60. I enjoyed life.	0	1	2	3

	Less than 1 day	1 – 2 days	3 – 4 days	5 – 7 days
61. I had crying spells.	0	1	2	3
62. I felt sad.	0	1	2	3
63. I felt that people disliked me.	0	1	2	3
64. I could not get “going”.	0	1	2	3

Feelings About Life

Directions: Here are some statements about life in general that people feel different ways about. Read each statement on the list and circle at right the number that best describes how you feel about the statement.

	Agree	Disagree	Unsure
65. As I grow older, things seem better than I thought they would be.	1	2	3
66. I have gotten more of the breaks in life than most of the people I know.	1	2	3
67. This is the dreariest time of my life.	1	2	3
68. I am just as happy as when I was younger.	1	2	3
69. My life could be happier than it is now.	1	2	3
70. These are the best years of my life.	1	2	3
71. Most of the things I do are boring or monotonous.	1	2	3
72. I expect some interesting and pleasant things to happen to me in the future.	1	2	3

	Agree	Disagree	Unsure
73. The things I do are as interesting to me as they ever were.	1	2	3
74. I feel old and somewhat tired.	1	2	3
75. As I look back on my life, I am fairly well satisfied.	1	2	3
76. I would not change my past life even if I could.	1	2	3
77. Compared to other people my age, I make a good appearance.	1	2	3
78. I have made plans for things I'll be doing in a month or a year from now.	1	2	3
79. When I think back over my life, I didn't get most of the important things I wanted.	1	2	3
80. Compared to other people, I get down in the dumps too often.	1	2	3
81. I've gotten pretty much what I expected out of life.	1	2	3
82. In spite of what some people say, the lot of the average man is getting worse, not better.	1	2	3

APPENDIX B

IRB Approval

GEORGIA STATE UNIVERSITY INSTITUTIONAL REVIEW BOARD

915C 9A0036
 13 Gilmer Street SE Unit 3
 Atlanta GA 30303-3283
 In Person: 220 Alumni Hall
 Phone: 404/651-4689
 Fax: 404/654-3828

February 20, 2004

**MEMORANDUM**

TO: Celia Hay
 Keo, Carolyn
 Nursing

FROM: Robert H. Curry
 Institutional Review Board

RE: Approval of Human Subjects Application No. H04253
 Type of Review: Expedited
 Approval Period: 02/19/2004 – 02/18/2005

The Georgia State University Institutional Review Board reviewed and **approved** your IRB protocol entitled "Quality of Life of Older Hemodialysis Patients", and your informed consent(s). The approval period is listed above.

Approval periods are one (1) year in length. This protocol **must be renewed at least 30 days before** 02/18/2005 if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, please visit our website at www.gsu.edu/irb.

RHC:sdh

Federal Wide Assurance Number: 00000129

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