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THE SYMPTOM EXPERIENCE OF PATIENTS WITH
END-STAGE RENAL DISEASE ON HEMODIALYSIS

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THE SYMPTOM EXPERIENCE OF PATIENTS WITH END STAGE RENAL DISEASE ON HEMODIALYSIS

By

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ABSTRACT

THE SYMPTOM EXPERIENCE OF PATIENTS WITH END STAGE RENAL DISEASE ON HEMODIALYSIS

By

Anita Marie Jablonski

The primary purpose of this study was to document the symptom experience of End-Stage Renal Disease (ESRD) patients on hemodialysis as the first step in determining if there is a need for improved symptom management. To accomplish this goal, an in-depth examination of the symptom experience associated with ESRD was completed. A convenience sample consisted of 130 hemodialysis patients, ages 22 to 82 years, recruited from two in-center dialysis clinics. Structured interviews were conducted during dialysis sessions using a demographics questionnaire, the Chemistry Abnormality Score, the Hospital Anxiety and Depression Scale, an 11-item multidimensional symptom scale and corresponding relief scale, and the Ferrans' and Powers' Quality of Life Index. Patients reported a high number and variety of distressing symptoms, many of which were not satisfactorily relieved. Furthermore, high levels of symptoms and low levels of relief were linked to diminished QOL. These results indicate that further investigation of the level of relief patients obtain from their symptoms as well as effective strategies to improve symptom management is warranted.

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Chapter 1

INTRODUCTION

According to the United States Renal Data System (USRDS) (2002), nearly 400,000 persons suffer from end-stage renal disease (ESRD). This condition requires long-term dialysis or transplantation to sustain life because the kidneys have lost the ability to remove metabolic waste products and maintain internal homeostasis. Due to the lengthened lifespan made possible by modern science, as well as the escalating elderly population, the number of patients who will require treatment for ESRD is expected to rise (Reikes, 2000). In fact, the incidence of ESRD is increasing at a rate of 5% per year and the prevalence has doubled since 1988 (Reikes, 2000). This growth in the ESRD population represents a major public health problem that affects individuals and society.

Of major concern are the costs associated with ESRD. The illness and its treatment necessitate lifestyle changes that are costly both economically and personally. The fiscal survival of the family unit is often jeopardized by employment changes as well as the substantial costs of care (Sloan, 1999). The stress of coping with a severe chronic illness erodes the emotional stability of the patient and family. Physiological alterations that accompany ESRD and hemodialysis give rise to additional comorbid conditions and a variety of symptoms that exact a toll as well. Because ESRD impacts every aspect of life, it threatens the ability of patients and their families to maintain an acceptable quality of life (QOL) (Ferrans & Powers, 1993).

The costs to society are also an issue. Medicare subsidizes the treatment of over 90% of afflicted persons (Reikes, 2000). In 1991 the charge to the government for the ESRD program was $5 billion (Rettig & Levinsky, 1991). Expenditures currently exceed

$12.5 billion, representing 5.8% of the entire Medicare budget (USRDS, 2002). In light of this financial outlay, it is understandable that there is considerable interest in the quality of the care ESRD patients receive.

This concern was first evident in 1987 when Congress enacted the Omnibus Reconciliation Act (OBRA). The OBRA legislation mandated that the health care services purchased by the government on behalf of ESRD beneficiaries be monitored for quality (Rettig & Levinsky, 1991). Congress delegated this task to the Institute of Medicine (IOM). The ensuing IOM study assessed a number of traditional outcomes including mortality, infection rates, and laboratory values. Less conventional quality indicators such as patient reported symptoms, well-being, and QOL were also examined (Rettig & Levinsky, 1991). Inclusion of these outcomes signaled a growing emphasis on how well the health care system meets the psychosocial as well as the physical needs of patients living with chronic illnesses that require treatment over an extended period of time.

In recent years, symptom relief and QOL have assumed greater emphasis as outcomes of care. Especially in the cancer population, palliative care services that specialize in symptom management have become a routine component of the treatment plan. Patients in the later stages of other chronic illnesses such as congestive heart failure and chronic lung disease have also benefited from these services. Patients who suffer from ESRD are rarely recipients of palliative care despite the fact that their illness as well as its treatment produces unpleasant symptoms.

Although some renal experts have voiced the need for palliative care in the ESRD population, the call has gone unheeded by the general healthcare community (Moss & the

ESRD Workgroup, 2001; Poppel, Cohen, & Germain, 2001). However, the need for palliative care has not been well documented empirically. The symptom experience associated with ESRD has been described to a limited extent in the nephrology literature, focusing mainly on individual symptoms and their severity or frequency. Equally lacking is research that verifies the level of symptom relief achieved by ESRD patients and the extent to which unrelieved symptoms influence QOL (Hoffart, 1995). Therefore, the primary aim of this exploratory study was to generate a comprehensive description of the symptom experience of ESRD patients, including the interplay among symptoms, level of symptom relief, and QOL. Filling in the knowledge gaps surrounding symptom experience is necessary to achieve the ultimate outcome of this investigation, namely, to determine whether there is a need for improved symptom relief to enhance the QOL of ESRD patients.

Chapter 2

REVIEW OF THE LITERATURE

Only 50 years ago, patients diagnosed with chronic, irreversible renal failure faced certain death. Since that time, however, scientific innovations have resulted in effective treatment for individuals who have lost kidney function. The development of renal replacement therapy (RRT), including dialysis and transplantation, has made it possible to prolong the lives of patients even after they progress to end-stage renal disease (ESRD).

Of all forms of RRT, hemodialysis is the treatment of choice for the majority of ESRD patients. Approximately 87% of incident (i.e., at the time of first regular dialysis) patients begin treatment with hemodialysis (United States Renal Data System [USRDS], 2002). Sixty-five percent of prevalent (i.e., known to be receiving treatment for a period of time) dialysis patients less than 65 years of age undergo this form of therapy. The proportion rises to 85% for prevalent dialysis patients over 65 (USRDS, 2002). Because of the predominance of hemodialysis as the preferred treatment modality, this investigation focused on this subgroup of the ESRD population.

Although hemodialysis is a life saving therapy, it is not without unpleasant side effects. The underlying disease process and the presence of additional comorbid conditions further add to the number and variety of symptoms experienced by hemodialysis patients. Undocumented clinical observations suggest that many of these symptoms are not adequately controlled and that healthcare providers' symptom management efforts have been inadequate or poorly informed (Poppel, Cohen, & Germain, 2001).

It is proposed that the efforts to control unpleasant symptoms associated with hemodialysis and ESRD would be enhanced by the use of palliative care strategies. This recommendation is strongly endorsed in a recent report compiled by the ESRD Workgroup, a subgroup of The Robert Wood Johnson Foundation program Promoting Excellence in End-of-Life Care (Moss & the ESRD Workgroup, 2002). Following a comprehensive review of the current state-of-care, the subgroup concluded that there is an urgent need for palliative care in the ESRD population.

Although considered to be a critical component of comprehensive care, ESRD patients are rarely the recipients of palliative care services. The reason lies in the traditional view of palliative care as a service limited to cancer patients who opt to forgo aggressive, curative treatment. In this paradigm, curative care and palliative care are viewed as two distinct entities, such that active treatment ends when palliative care begins (see Figure 1). Because the majority of ESRD patients continue active treatment, palliative care is not considered a routine part of care.

Active treatment and palliative care are not mutually exclusive, especially in a disease that is at the same time chronic and life-limiting. In an integrated model, both active treatment and palliative care are offered concurrently, beginning at the time of diagnosis of an incurable illness (see Figure 2) (Kristjanson, 2001). In this paradigm, use of palliative care strategies begins at the time of diagnosis and increases as the patient nears death. This model is especially relevant to the care of cancer patients who begin with active treatment in hopes of a cure and end life in hopes of a comfortable death.

A modification of the concurrent model of palliative care is suggested for the ESRD population (see Figure 3). End-stage renal disease patients differ from other

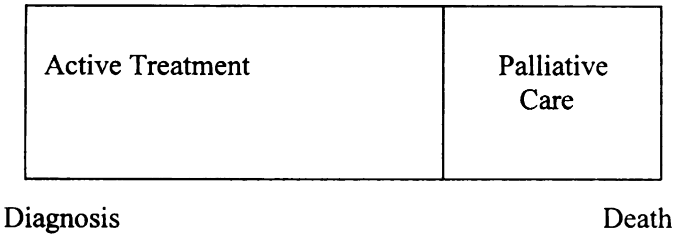

Figure 1. Traditional model of palliative care

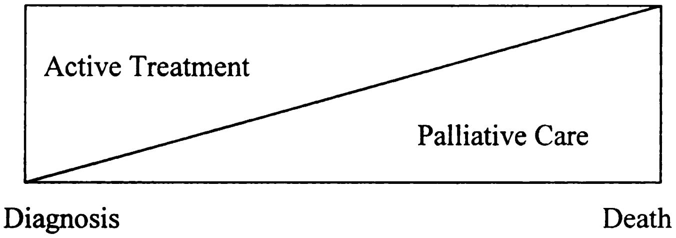

Figure 2. Integrated model of palliative care

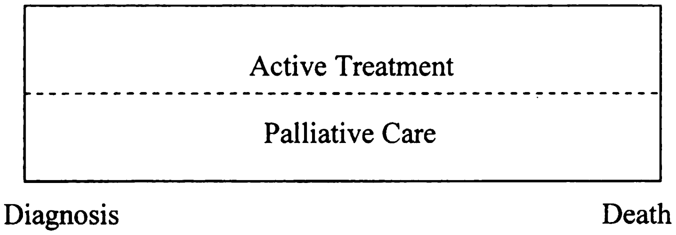

Figure 3. Suggested model of palliative care for ESRD patients

chronically ill individuals in that they are forced to confront end-of-life (EOL) issues from the time of diagnosis, facing certain death unless they receive active treatment in the form of RRT. Even with RRT, these patients live with the reality of a shortened lifespan. Data provided by the USRDS (2002) indicate that expected remaining lifetimes for dialysis patients are one-quarter to one-fifth those of the general population. Furthermore, adjusted first year mortality rates are 21.5% for dialysis patients, with rates remaining remarkably constant through the fifth year of dialysis (Reikes, 2000). End-stage renal disease patients also experience a multitude of unpleasant symptoms as a result of both the illness and its treatment. It is argued that the integrated model of palliative care requires modification for this unique patient population. In the revised version of the model, active treatment and palliative care share equally in the treatment plan from the time of diagnosis to death.

Both versions of the concurrent model are supported by the World Health Organization (WHO) and are consistent with its definition of palliative care. According to the WHO (2001),

> Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and psychological, social and spiritual problems, is paramount. The goal of palliative care is the achievement of the best QOL for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with active treatment.

This definition depicts palliative care as a service that can be offered along with active therapy as well as after the failure of curative treatment (Kristjanson, 2001).

The concurrent model of palliative care has not yet been accepted by the healthcare community. In the present healthcare system, most palliative care services are offered through hospice and still tend to be an option confined to EOL (Vachon, 2001). In addition, reimbursement for hospice benefits is tied to criteria that limit the ability of ESRD hemodialysis patients to take advantage of these services that specialize in symptom relief. To make use of the Medicare Hospice Benefit, patients must have a 6 month prognosis and forgo aggressive treatment (U. S. Department of Health and Human Services Health Care Financing, 2003). Although the Healthcare Financing Administration requires that prognosis be based only on the physician's best knowledge of the disease course, it is difficult to anticipate length of survival in this population (Barriers to hospice, 2000). In addition, few patients would decline aggressive treatment (i.e., dialysis) in exchange for hospice care. As a result of these two criteria. ESRD patients are rarely referred to hospice for palliative care.

Either modification of the current Medicare criteria for admission to hospice or the creation of a separate benefit to cover ESRD patients is needed to assure access to palliative care services currently available. Yet another alternative is the employment of clinicians that specialize in palliative care in both nephrologists' offices and dialysis clinics. Programs to educate the clinical dialysis staff in palliative care strategies might also be put in place. The downside is that each of these options requires a financial commitment at a time when economic resources are limited.

However, these expenditures can be justified in light of the costs associated with unrelieved symptoms. Poorly controlled symptoms often result in increases in both the utilization of health care resources and the economic costs of care (Wilson & Cleary, 1995).

Unmanaged symptoms are also expensive personally and financially in that they challenge an individual's capacity to engage in normal life activities, including employment. Furthermore, living with a chronically ill individual suffering from unrelieved symptoms affects the entire family unit in the struggle to maintain financial stability and an acceptable QOL.

Symptom relief is a primary goal of care as well as an indicator of the quality of care provided hemodialysis patients. Health professionals, who play a major role in helping patients manage their symptoms and achieve a satisfactory QOL, have a vested interest in advocating for changes that promote their efforts to achieve these objectives. To effectively campaign for change, however, healthcare providers must be armed with information that documents the need for palliative care services in the hemodialysis population. Data that provide this support are not currently available in the literature.

Research to explore and describe the symptom experience of hemodialysis patients is the first step in validating the need for specialized symptom management services. To accomplish this goal, the current study will examine several areas of the symptom experience of hemodialysis patients including: 1) the factors that influence symptoms, 2) the symptoms themselves, 3) strategies used by patients to relieve symptoms, 4) the level of relief achieved, 5) the relationships among symptoms, level of relief, and QOL, and 6) the impact of level of relief on the relationship between symptoms and QOL. The data that result from this study will either refute or confirm the assumption made in this discussion that hemodialysis patients live with unrelieved symptoms that affect their QOL. Should this claim be validated, the next phase, to determine whether palliative care leads to improved symptom management and QOL, will be set in motion.

Theoretical Model

Theory of Unpleasant Symptoms

The theoretical model for this study is based on the middle range theory of symptom experience, The Theory of Unpleasant Symptoms (TOUS) (see Figure 4). Therefore, a summary of the TOUS will be presented first, followed by a description of the modified model that was the foundation for this investigation. The TOUS hypothesizes that symptom experience is comprised of influencing factors that cause or affect the nature of the symptoms, the symptoms themselves, and their consequences (Lenz, Pugh, Milligan, Gift, & Suppe, 1997). Further clarification of the model is presented below, beginning with a discussion of factors thought to influence symptom experience.

Influencing factors. The TOUS proposes that three categories of variables affect the occurrence and perception of symptoms; physiological, psychological, and situational (Lenz et al., 1997). Examples of physiological factors include electrolyte imbalance, the presence of pathological conditions, and altered nutritional status. The psychological category is comprised of variables such as mood, affect, and mental states of depression and anxiety. Situational factors refer to aspects of the social and physical environment that affect symptom experience. Examples include marital status, level of education, social support, environmental air quality, heat, and humidity. According to the TOUS, all three categories of influencing factors are interrelated and interact with one another to shape the overall symptom experience (see Figure 4) (Lenz et al., 1997).

Symptoms. Symptoms are conceptualized as multidimensional phenomena defined

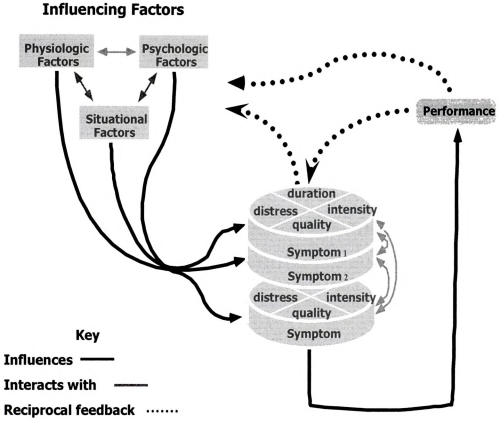

Figure 4. Theory of Unpleasant Symptoms

Note. From Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A., & Suppe, F. (1997). The middle-range Theory of Unpleasant Symptoms: An update. *Advances in Nursing Science, 19*(3), 14-27. Copyright 1997 by Lippincott Williams & Wilkins. Reprinted with permission.

by intensity, timing, distress, and quality (Lenz et al., 1997). Intensity refers to severity of the symptom. The time dimension includes both the frequency of oc and the duration of the symptom. Distress is the degree to which a person is bot symptom. Lastly, quality is the way in which a symptom is manifested and ofte by the descriptors used to characterize it (Lenz et al., 1997).

Symptoms rarely occur in isolation. More often, patients experience mu symptoms simultaneously (Dodd, Miaskowski, & Paul, 2001b; Lenz et al., 199 TOUS asserts that the perception of a single symptom is different than the sens the same symptom when it occurs in combination with others. Co-occurring sy are thought to interact to produce an experience that is multiplicative rather tha (Lenz et al., 1997).

Performance. The final component of the TOUS is performance, the co of the total symptom experience. Performance includes both functional and cog activities (Lenz et al., 1997). Functional performance is defined as physical fun social functioning, and the ability to accomplish normal role related tasks. Cogn performance refers to the capacity to think, concentrate, and problem solve. The suggests that the presence of symptoms results in reduced performance ability (al., 1997).

Modified study model.

The model that guides this study is an adapted version of the TOUS. Re made in the TOUS resulted from both a review of the literature and a unique conceptualization of the symptom experience that includes symptom relief (see

Influencing factors. This component of the TOUS was included in the s

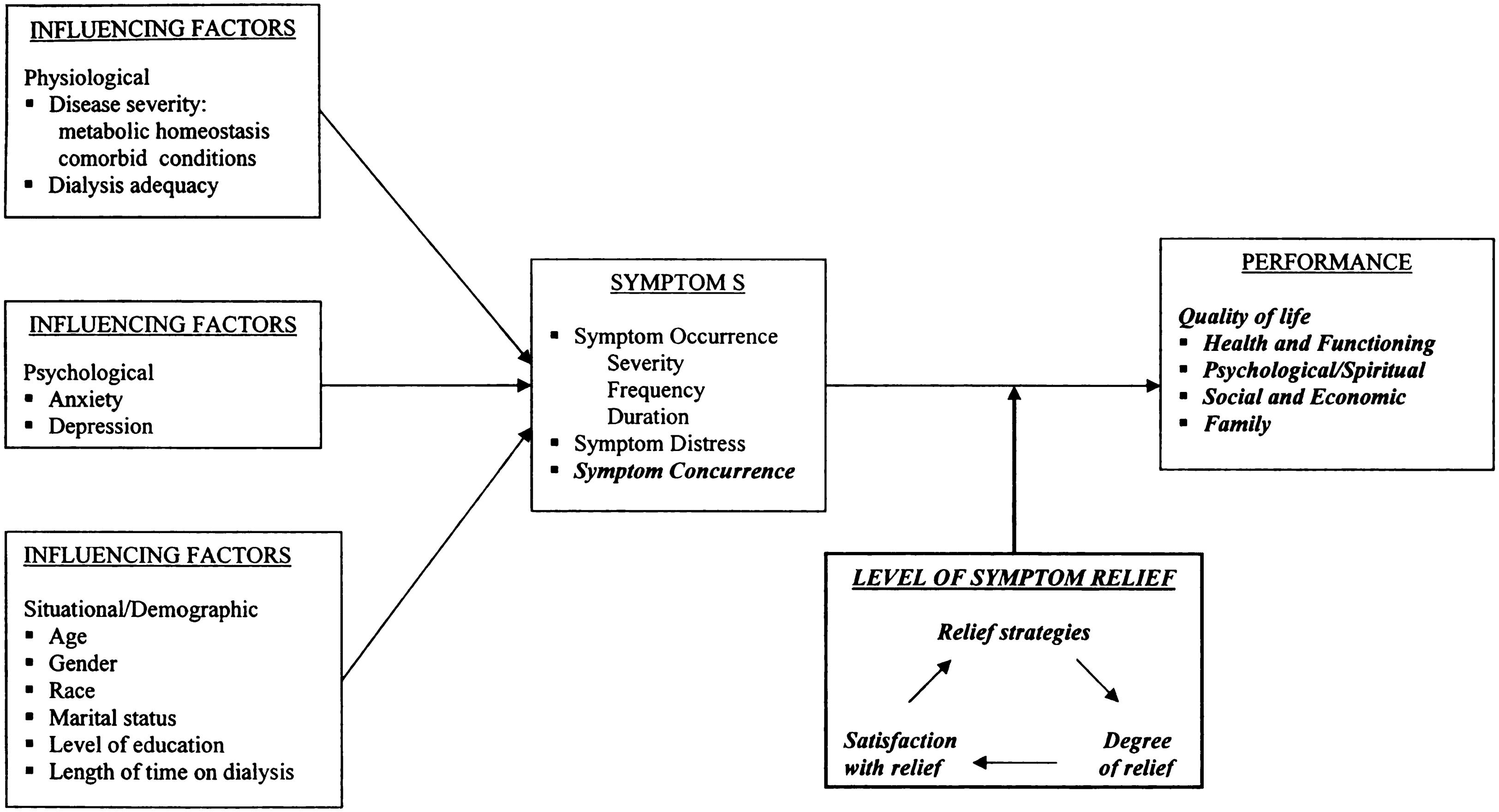

Figure 5. Theoretical model of the symptom experience of hemodialysis patients

Note: Modifications to the Theory of Unpleasant Symptoms are in italics and bolded.

model unchanged. As in the TOUS, three categories of factors influence the presence and perception of symptoms, including the physiological, psychological, and situational/ demographic. Physiologic factors of interest include metabolic homeostasis and numbers of comorbid conditions as indicators of disease severity. Dialysis adequacy, a gauge of the effectiveness of hemodialysis treatment, is also included as a physiological factor that potentially influences symptoms. Anxiety and depression represent psychological influencing factors. Finally, age, gender, race, marital status, level of education, and length of time on dialysis are the situational factors that are the focus of this study.

Symptoms. The symptom component of the TOUS was modified following a review of the literature. As depicted in the revised study model, the dimensions of symptoms include: occurrence and distress (McDaniel & Rhodes, 1995; Rhodes & Watson, 1987). Symptom occurrence includes the following dimensions: severity (intensity), frequency (how often the event occurs within a given time frame), and duration (length of time the event lasts) (McDaniel & Rhodes, 1995). Symptom distress is the degree or amount of physical and/or mental upset experienced from a specific symptom (Rhodes & Watson, 1987). Both occurrence and distress describe the experience of individual symptoms (Rhodes & Watson, 1987).

An additional dimension, concurrence, has been added to the model. Concurrence describes the coexistence and interaction of symptoms and, together with occurrence and distress, completes the multidimensional conceptualization of symptoms. Concurrence is considered an important aspect of symptoms but it is not labeled as a separate dimension in the TOUS (Lenz et al., 1997). Doing so emphasizes the importance of the interaction of multiple symptoms in shaping the overall symptom experience.

Level of Symptom Relief

Another modification of the TOUS is the inclusion of level of symptom relief as a significant component of symptom experience in ESRD. Symptom relief strategies, degree of relief achieved, and perceived satisfaction with relief define this component of the model. Symptom relief strategies are the methods used by patients to achieve a level of symptom relief. Strategies include those that are prescribed by healthcare professionals as well as any that are self initiated. Degree of relief is defined as a subjective evaluation of the extent to which symptoms are relieved. Perceived satisfaction with relief is the extent to which the individual is content with his/her current level of relief from symptoms. In the study model, level of symptom relief moderates the effect of symptoms on QOL.

Performance. The TOUS includes the ability to perform functional and cognitive activities as the consequence of symptom experience. However, in the current study, this component has been amended to include a more global performance measure, QOL. Ferrans'(1997) conceptualization of QOL is integrated into the study model as the chosen performance indicator. Based on the view that QOL is a subjective concept dependent on the individual's perspective, Ferrans (1997) defined QOL as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (p. 113).

Ferrans' model encompasses four domains: health and functioning, psychological/spiritual, social and economic, and family. The health and functioning domain includes the following aspects of life: usefulness to others, physical independence, ability to meet family responsibilities, own health, energy, worries, contro over own life, leisure time activities, potential for a long life, ability to travel, sex life, health care, and potential for a happy old age. Satisfaction with life, happiness in general satisfaction with self, achievement of personal goals, peace of mind, personal appearanc and faith in God are components of the psychological/spiritual domain. Elements of the social and economic domain are standard of living, financial independence, home, neighborhood, job/unemployment, friends, emotional support from others, and educatio Finally, family happiness, children, relationship with spouse, and family health are factors that comprise the family domain. QOL is a product of both the degree of satisfaction with aspects of life in each domain as well as the perceived importance of those aspects of life to the individual. The overall study model predicts that symptoms directly affect QOL by their influence on an individual's satisfaction with areas of life that he/she considers important.

In summary, the TOUS and the relationships it proposes among influencing factors, symptoms, and performance provide the foundation upon which the present stud model was built. The theory hypothesizes that a variety of physiologic, psychologic, and situational/demographic factors potentially influence symptoms which, in turn, affect performance. For the current study, however, the TOUS was modified to include level o symptom relief as a significant component of total symptom experience. The dimension of concurrence was also specifically labeled to emphasize its importance to the overall symptom experience. The final model is presented in Figure 5.

Symptom Experience of Hemodialysis Patients

The current state-of-knowledge regarding the symptom experience of hemodialysis patients will be discussed within the study's theoretical framework described in the previous section. An overview of studies related to each component of the model will be presented. In some instances research is limited, reinforcing the significance of the present investigation.

Influencing Factors

A variety of physiological, psychological, and situational/demographic factors are thought to precipitate and/or modify the symptoms hemodialysis patients experience. A select few are of particular interest to this study including: disease severity and dialysis adequacy (physiological); anxiety and depression (psychological); and age, gender, race, marital status, level of education, and length of time on dialysis (situational/demographic). The relationship between some of these variables and symptoms has not been previously explored in the ESRD population. Others have been examined but with conflicting results.

Influencing Factors: Physiological

As depicted in the study model, it is hypothesized that both disease severity and dialysis adequacy affect symptoms. The term 'disease severity' is defined as the degree of physiological disturbance present (Craven, Littlefield, Rodin, & Murray, 1991). The degree of metabolic homeostasis and the presence of comorbid conditions are indicative of overall physiological disturbance (Craven et al., 1991). Both are included as determinants of disease severity in the current study.

Adequacy of dialysis refers to the delivered 'dose' of dialysis, namely the amount of effective dialysis a patient achieves in one treatment session (Curtis, 2004). The measurement of urea clearance, as expressed by Kt/V (i.e., dialyzer clearance x time / volume of body water), has been widely accepted as one marker of dialysis adequacy

(National Kidney Foundation [NKF], 2001). Kt/V represents the rate at which urea, a waste product, has been removed from the blood. Consistent with national guidelines, Kt/V is the indicator of dialysis adequacy chosen for this study.

Metabolic homeostasis. Metabolic homeostasis refers to the body's ability to maintain relative constancy of the internal environment (Anderson , Anderson, & Glanze, 1998). Laboratory values are measures of the body's ability to maintain homeostatic balance and one gauge of disease severity (Griffin, Friend, & Wadhwa, 1995). Some research has examined the effect of biochemical imbalances on the symptoms experienced by hemodialysis patients. However, findings are inconclusive, particularly in relation to the commonly occurring symptoms of fatigue and problems sleeping (Brunier & Graydon, 1992; Cardenas & Kutner, 1982; McCann & Boore, 2000).

Although fatigue is one of the most prevalent symptoms reported by hemodialysis patients, its causes are not well understood (Srivastava, 1989). The toxic effects of uremia combined with low hemoglobin levels that are typical of ESRD are often implicated as precipitating factors. However, research has not consistently demonstrated the relationship between these laboratory parameters and fatigue. McCann and Boore (2000) found no association between biochemical variables, including urea and anemia, and fatigue in their sample of 50 hemodialysis patients. Likewise, anemia did not contribute significantly to the fatigue reported by 43 patients in another investigation conducted by Brunier and Graydon (1992). These findings corroborated those of an earlier study by Cardenas and Kutner (1982), who observed no correlation between fatigue ratings and hematocrit or any of the other lab values examined, including BUN and creatinine.

Some research related to sleep disturbances also contradicts the conventional thinking which links uremic toxins to disordered sleep patterns (Daugirdas & Ing, The sleep patterns of 54 hemodialysis patients were examined by Walker, Fine, an Kryger (1995) and no correlation was found between urea and creatinine levels an problems sleeping.

In a descriptive study of 191 ESRD patients, Barrett and colleagues (1990) note a significant correlation between sleep disturbances and urea levels. However strength of the association ($r = 0.19, p \leq 0.05$) called into question the clinical rele of this finding. Additional significant correlations between laboratory indices and symptoms were demonstrated in this study as well. Levels of alkaline phosphatase, calcium, and uric acid were positively related to joint pain. Serum bicarbonate leve negatively correlated with cramps. As was the case with urea and sleep disturbanc strength of the relationship among these variables was low.

Finally, Wolcott, Nissenson, and Landsverk (1988) examined the relations between laboratory values and symptoms using global measures of each of the var The Chemistry Abnormality Score (CAS) summarizes the results of 13 routinely performed biochemical tests in dialysis patients. The Active Clinical Problems Sc (ACPS) summarizes 36 symptoms/signs and recent hospitalizations. No significan correlation was noted between these two scores.

Based on the research available, it is not yet clear whether there is a signifi relationship between biochemical indices and the symptoms reported by hemodia patients. It seems reasonable to assume that disturbances in homeostatic balance m precipitate somatic symptoms. However, this proposed connection requires further investigation.

Comorbid conditions. The presence of comorbid conditions is the second determinant of disease severity of interest to this study. Comorbidity is defined as a significant concurrent disease in addition to ESRD which involves organs other than the kidneys but which may also be responsible for the renal failure (Khan, 1998). Again, research linking comorbidity and symptoms is sparse and inconsistent.

Merkus and colleagues (1999) examined the relationship between a variety of clinical characteristics and physical symptoms in a sample of 120 chronic hemodialysis patients. The clinical variables included the underlying kidney disease, lean body mass, a selection of laboratory values, hydration status, residual renal function, and comorbidity. Of these factors, only a medium to high comorbidity-age index was significantly associated with a higher symptom scores. This index, based on age and presence of comorbid conditions, indicated that patients over the age of 70 years with one or more comorbidities experienced greater symptom burden.

Conversely, comorbidity was not among the significant correlates of somatic symptoms reported by Barrett, Vavasour, Major, & Parfrey (1990) in an earlier study of 73 hemodialysis patients. There was also no correlation found between comorbid conditions, such as cardiovascular disease, and fatigue in a study conducted by Cardenas and Kutner (1982).

Dialysis adequacy. Dialysis adequacy is also thought to play an influential role in shaping the symptoms that hemodialysis patients experience. When kidney failure occurs, the body loses its ability to remove the toxic end-products of metabolism. As waste products accumulate, symptoms of the uremic syndrome appear. Hemodialysis is instituted to compensate for loss of renal function, restore homeostatic balance, and reduce unpleasant symptoms. The effectiveness with which hemodialysis perform functions is quantified by Kt/V, as defined earlier in this discussion. The current g standard is a Kt/V ≥ 1.2 (NKF, 2001). The logical deduction is that Kt/V values be that norm would be associated with increasing symptoms of uremia. Although rese does not consistently validate this hypothesis, the relationship has been demonstra

Morton and colleagues (1996) examined the relationship between dialysis adequacy and QOL in a sample of 55 hemodialysis patients. Measured using the subscales of the Rand 36 Item Health Survey and Kt/V values, the correlations bet fatigue/energy and pain subscales and Kt/V were not significant. Likewise, in the conducted by McCann and Boore (2000) and Merkus et al. (1999) previously disc dialysis adequacy was included as one of the biochemical variables examined. Nei investigation found a significant relationship between Kt/V and symptoms.

Data presented by Hamilton and Locking-Cusolito (1998) contradict these In a pilot study that followed 11 hemodialysis patients for 3 months following initi of treatment, symptom burden decreased with adjustments in therapy that produce increased Kt/V values. Degree of fatigue also declined. The authors cautioned that factors not examined may have also contributed to improved symptom status. In a the small sample size limited their ability to state conclusively that more effective dialysis was associated with lower symptom burden.

However, studies examining the benefits of daily hemodialysis provide add evidence of the relationship between dialysis adequacy and symptoms. Recent rese has demonstrated that Kt/V levels increase with short daily treatments. Improveme intradialytic symptomatology (i.e., nausea, cramps, and dizziness), post-dialysis fa and uremic symptoms have accompanied the rise in Kt/V values (Curtis, 2004; Lindsay, Kortas, & the Daily/Nocturnal Dialysis Study Group, 2001; Maduell et al., 2003). Since none of these studies included sample sizes greater than 10, careful interpretation of these findings is warranted. Regardless, these studies justify inclusion of dialysis adequacy as an influencing factor in this study.

The research presented illustrates the inconsistencies in the literature surrounding the relationship between physiologic factors (i.e., disease severity and dialysis adequacy) and symptoms experienced by hemodialysis patients. Neither disease severity nor dialysis adequacy has been established unequivocally as factors that do or do not influence symptoms. Therefore, these variables were explored in this investigation in an effort to further clarify their connection.

Influencing Factors: Psychological

The second category of factors that are hypothesized by the study model to influence symptoms is the psychological. The interaction of an individual's state of mind and physical condition has long been established in the literature. Symptoms are defined as subjective indicators of change in a condition as perceived by the individual (Anderson, Anderson, & Glanze, 1998). Psychological status is the filter through which these subjective perceptions are interpreted. Patient reports of symptoms are outcomes of these perceptions (The University of California, San Francisco School of Nursing Symptom Management Faculty Group, 1994; Dodd et al., 2001a).

Anxiety and depression are two disorders that influence the perception and interpretation of symptoms. Previous research has verified the relationship between these mental states and the symptoms experienced by persons living with chronic illnesses

(Simon, 2001). Since anxiety and depression are commonly noted in the ESRD population, their inclusion as psychological influencing factors is critical to understanding the symptom experience of hemodialysis patients (Christensen & Ehl 2002; Kimmel, 2002).

Anxiety and depression have been linked to specific symptoms such as fatig Significant correlations between both disorders and fatigue were noted by McCann Boore (2000) in a study of 25 hemodialysis patients. To eliminate the confounding o physical symptoms of ESRD and mental state, anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS). This tool includes items solely on psychic symptoms of neurosis and excludes the somatic symptoms that co with physical illness (Zigmond & Snaith, 1983). The correlation between anxiety an depression and fatigue was demonstrated despite the existence of physical illness in study group (McCann & Boore, 2000).

Cardenas and Kutner (1982) measured depression but not anxiety in their stu fatigue in 137 dialysis patients. They concluded that depression is a principal cause fatigue. This inference was supported by the fact that patients who experienced significant fatigue upon arising, when its level would be expected to be its lowest, al had scores that indicated significant clinical depression.

Depression and anxiety have also been found to be associated with overall symptom experience. Killingworth and Van Den Akker (1996) examined the relatio between mental state and symptom status in a sample of 170 dialysis patients. Using HADS to measure anxiety and depression, they found significant correlations betwe both the anxiety and depression subscales and uremic symptoms that accompany ren failure. As noted previously, the HADS does not include somatic symptoms commonly experienced by physically ill individuals. The assessment of anxiety and depression in this sample was based solely on the presence of psychological symptoms.

Likewise, in their study of 73 hemodialysis patients, Barrett et al. (1990) examined the connection between psychological factors and the severity of eight somatic symptoms including: tiredness, sleep disturbance, cramps, pruritis, headache, nausea, dyspnea, and joint pain. Affect was measured using a scale comprised of 11 emotions that the researchers considered of importance in ESRD, among them feeling sad and scared. The severity of each somatic symptom was significantly related to indices of affect. Although the affect scale used was not a specific measure of anxiety or depression, it was able to demonstrate a relationship between psychological well-being and symptoms patients experienced.

The empirical evidence corroborates the presence of a relationship between psychological status and symptoms in the ESRD population. Anxiety and depression have been consistently linked to symptom status. Whether anxiety and depression intensify the perception of symptoms or anxiety and depression are the result of symptom burden remains uncertain. However, there exists a clear link that validates the inclusion of anxiety and depression in the theoretical model for this study.

Situational/demographic factors. Examination of the connection between situational/demographic variables and symptoms has not been a major focus of previous research. However, a number of these variables conceivably affect reporting of symptoms. Of interest to this study are age, gender, race, marital status, level of education, and length of time on dialysis.

Age is frequently reported to describe the study sample and not often considered a major variable of interest. Research investigating the effect of age on the symptoms reported by hemodialysis patients is sparse. Age was positively correlated with symptom burden when measured in combination with comorbidity in the study by Merkus et al. (1999) mentioned earlier. Older age and greater comorbidity were associated with higher levels of symptomatology. The effect of age alone was not reported. Similarly, Barrett et al. (1990) found that age was related to reports of headache and nausea in their study of the correlates of somatic symptoms in patients on dialysis. Age was not a major focus of either of these studies.

Gender. Like age, the impact of gender on the symptoms experienced by hemodialysis patients has not been documented empirically. Only one study was found that included gender in the analysis of symptom reporting. In their study of fatigue in dialysis patients, Cardenas and Kutner (1982) found that average fatigue ratings were similar for men and women. No other studies specific to ESRD were located that examined the relationship between gender and symptoms. It is yet to be determined if symptom response is gender specific in the hemodialysis population.

Race. Investigation of the interaction of race and symptoms has been similarly neglected. In the only study found that examined the differences in the symptoms reported by race, Kutner and colleagues (2000) discovered that Blacks were significantly less likely than Whites to complain of nausea, sexual dysfunction, and general fatigue. Black patients also reported less post dialysis fatigue and fewer hours needed for recovery following treatment. No other racial groups were included in this study. Research that investigates the relationship between race and symptoms is notably lacking in the nephrology literature.

Marital status and level of education. Research relating marital status and level of education with symptoms is sparse, with these variables most often reported only as descriptors of sample demographics. However, Merkus et al. (1999) did include these variables in their analysis but did not find an independent association between them and the symptoms reported by hemodialysis patients. McCann and Boore (2000) also failed to observe any relationship between marital status of dialysis patients and level of fatigue. Sample size in both studies was comparatively small, which may account for the lack of significant findings. Because marital status and level of education have not been adequately studied, their influence on symptoms warrants further investigation.

Length of time on dialysis. It has been suggested that the experience of ESRD can be described in relation to an illness trajectory, with different phases emerging over time (Jablonski, 2004). Each phase is thought to be characterized by unique physical and psychological events, tasks, and shifting demands (Corbin & Strauss, 1992; Rolland, 1987). In light of this conceptualization, the experience of dialysis, as well as the symptoms that accompany it, might be expected to vary over time.

Neither the concept of an ESRD illness trajectory nor the effect of time on dialysis on symptoms has been researched. Only two studies were found that examined the correlation between length of time since initiation of treatment and symptoms and in neither was it a major focus. In their sample of 137 hemodialysis patients, Cardenas and Kutner (1982) reported that those on hemodialysis for greater than 4 years experienced lower levels of fatigue than those treated for a shorter time. However, in a smaller sample of 39, McCann and Boore (2000) did not observe this relationship. Additional research is needed to establish whether or not a relationship exists between time since initiation of dialysis and symptoms.

The lack of studies examining the influence of situational/demographic variables on self-reported symptoms is striking. Furthermore, this discussion of all of the categories of influencing factors, especially the physiological and situational/demographic, has illustrated the need for clarification of their connection to symptoms. Although many of the factors included in the present study are not modifiable, knowledge of those factors that are related to higher levels of symptoms may help detect patients at risk for higher levels of symptoms. Identification of those factors that are modifiable may help to pinpoint areas for intervention as well.

Symptoms

Research indicates that ESRD patients suffer from an array of troublesome symptoms. Some of them are triggered by specific organic diseases, such as dyspnea due to chronic lung disease or joint pain caused by gout. Others are difficult to attribute to a specific organic pathology (e.g., problems sleeping, fatigue, and headache). Still others are related to treatment side effects (e.g., cramps and nausea).

Regardless of etiology, a number of studies have identified the symptoms that are commonly experienced by hemodialysis patients. Fatigue is often the most prevalent symptom reported (Barrett et al., 1990; McCann & Boore, 2000; Merkus et al., 1999; Parfrey et al., 1987; Parfrey, Vavasour, Henry, Bullock, & Gault, 1988; Parfrey et al., 1989). Other symptoms that have been found to occur in greater than 20% of the ESRD population include: itching, headache, sleep disturbance, cramps, pain (joint, chest, abdominal), shortness of breath, nausea/vomiting, and muscle weakness (Parfrey et al., 1988).

Although research has documented the specific symptoms that are most common among dialysis patients, an exploration of the multidimensional nature of symptoms is yet to be completed. Studies have focused primarily on the presence/absence of symptoms and their associated severity or frequency of occurrence. Other dimensions of symptom experience, such as distress and concurrence have been overlooked or inconsistently described.

McCann and Boore (2000) measured only the severity of symptoms in their study of fatigue. Hemodialysis patients reported tiredness as the most severe symptom. Muscle weakness, joint pain, and lack of sleep rounded out the top four symptoms in terms of severity. Likewise, Parfrey and colleagues (1987) examined the severity of symptoms experienced by 107 hemodialysis patients. Tiredness was once again rated the most severe, followed by cramps, headaches, itching, and sleep disturbances in descending order.

Killingworth and Van Den Akker (1996) also described only one symptom dimension, in this instance, frequency of occurrence. Greater than 20% of the hemodialysis patients in their study experienced tiredness, itching, sleeping problems, and muscle weakness on most days. Apparent from this and studies of symptom severity, tiredness is one of the most problematic symptoms for these patients.

Multiple dimensions of symptoms were intentionally assessed in only one study found in the literature. Parfrey et al. (1988) expanded a physical symptom scale developed in an earlier study to incorporate a number of clinical features of symptoms, among them severity, duration, and frequency of occurrence. For example, it was noted that fatigue occurred every day in 65% of the sample and lasted for greater than 6 hours in 69% of those patients. Itching was reported to be a daily event for 70% of the patients, with a reported duration of over an hour for most of them (80%). These expanded descriptions of symptoms generate a more thorough understanding of the total experience. Distress and concurrence were not examined in this study.

A relatively new addition to the conceptualization of symptoms, concurrence has not been explored in studies of dialysis patients. However, concurrence was alluded to by McCann and Boore (2000) in their study of fatigue. On average, hemodialysis patients in their sample reported seven symptoms. There was a significant positive correlation found between fatigue severity scores and the number and severity of additional symptoms. This observation provides some evidence of an interaction among concurrent symptoms However, whether the nature of the interaction is multiplicative or additive is not evident from these findings.

Although the specific symptoms hemodialysis patients experience are well documented, their multidimensional characteristics are not. Previous investigations have focused on limited aspects of symptoms, typically occurrence and severity or frequency. Given the recent introduction of concurrence as a symptom dimension, it is not surprising that no research was found describing this dimension in ESRD. Consequently, a complete picture of symptoms is not yet available.

Level of Symptom Relief

As depicted in the theoretical model for this study, symptom relief strategies, degree of relief, and satisfaction with relief interact to define overall level of symptom relief. It is proposed that level of relief then moderates the impact of symptoms on QOL.

However, this relationship has not been documented in the literature. Research investigating the extent to which ESRD patients obtain relief from their symptoms is virtually nonexistent. Typically, the focus is on the presence/absence of symptoms rather than the amount of relief obtained or the methods used to manage them (Hoffart, 1995).

Only one investigation was found in which patients were questioned about symptom relief. In a study discussed previously in relation to symptom dimensions, Parfrey et al. (1988) asked dialysis patients several questions about each symptom they reported. For some of the symptoms, patients were asked if they took medications for relief. However, neither the adequacy of the relief nor the effectiveness of other interventions was investigated. Failure to investigate symptom relief results in a significant gap in knowledge of the total symptom experience associated with ESRD.

Performance

QOL is the final component of the symptom experience model that is the theoretical foundation of this study. QOL is a global performance indicator that represents overall satisfaction with the physical, psychological/spiritual, social/economic, and family aspects of life as well as their relative importance. The model depicts a direct link between symptoms and QOL, suggesting that symptoms diminish QOL by impacting areas of life that are important to an individual. Research has validated the positive relationship between symptoms and QOL proposed by the model.

Killingworth and Van Den Akker (1996) assessed the QOL of 70 hemodialysis patients using the Quality of Life Index—Dialysis Version (QLI) (Ferrans & Powers, 1985). Patients' total QLI scores were skewed toward the higher end, suggesting satisfactory QOL. They noted, however, a significant positive correlation between symptom severity and QOL. Those patients with the most intense symptoms reported the lowest level of QOL. Because the correlations between symptom scores and the subscales of the QLI were not reported, the influence of symptoms on different aspects of life cannot be determined.

The influence of symptoms on QOL was also assessed by Merkus et al. (1999) in a study of 120 incident chronic hemodialysis patients. Symptom burden was shown to be an independent determinant of diminished QOL, measured using the MOS SF-36. Physical component summary scores (PCS) and mental component summary scores (MCS) were calculated to summarize the eight scale profile. Symptom burden explained 17% of the variance in the PCS scores and 23% of the variance in MCS scores.

Srivastava (1989) examined the characteristics of chronic fatigue experienced by 27 hemodialysis patients and the impact on several aspects of functioning. A significant relationship between fatigue and QOL was found, with a higher levels of fatigue linked to lower perceived QOL. The majority of patients who reported a QOL of less than 90 (possible scores ranged from 0-100, low to high quality) also indicated that their QOL would improve appreciably if their tiredness was relieved.

The effect of symptoms on QOL was explored in a similar manner by Parfrey et al. (1988). In their study of the clinical features of six somatic symptoms (i.e., tiredness, cramps, itching, shortness of breath, headaches, and joint pain), patients were asked whether relief of each of the symptoms would improve their QOL by $\geq$ 10%. Patients indicated that relief of tiredness, cramps, and sleep disturbances would significantly improve their feelings of well-being.

Although a variety of factors undoubtedly interact to shape QOL, empirical evidence hints at the important influence of symptoms. In studies that have included symptoms as a correlate, the negative relationship between symptoms and QOL has been consistently demonstrated. The conclusion that symptoms diminish the perceived well-being of dialysis patients seems warranted, validating that link in the study's theoretical model.

Summary

Apparent from this review of the nephrology literature, the total symptom experience of hemodialysis patients has not been fully described. The present study contributes to the knowledge base by documenting the relationship that exists between specific physiological (disease severity and dialysis adequacy), psychological (anxiety and depression), and situational/demographic (age, gender, race, marital status, level of education, and length of time on dialysis) factors and the experience of symptoms. The literature abounds with inconsistencies regarding the most significant of these factors.

This research is also the first to examine the multidimensional nature of symptoms reported by hemodialysis patients. The level of relief that patients obtain from their symptoms will also be explored, adding unique information to the current understanding of symptom experience in ESRD. Finally, the ability of hemodialysis patients to maintain a satisfactory QOL is a major concern of healthcare professionals. Factors that are associated with diminished QOL will be identified to help direct their efforts to improve the lives of hemodialysis patients, especially in terms of improved symptom relief.

Ultimately, this study responds to an appeal made by the End-Stage Renal Disease Workgroup, a subgroup of The Robert Wood Johnson Foundation program

Promoting Excellence in End-of-Life Care (Moss & the End-Stage Renal Disease Workgroup, 2001). After extensive study of the current state-of-care, this group called for increased efforts to improve the lives of ESRD patients through the integration of palliative care within dialysis practice. The nephrology research community was challenged to help accomplish this goal through empirical validation of the benefits of palliative care to ESRD patients. Accepting this challenge, this investigation seeks to document the symptom experience of ESRD hemodialysis patients as the initial step in determining if there is a need for improved symptom relief. In doing so, it will justify further exploration of the benefits of palliative care to this vulnerable group of patients.

Chapter 3

METHODOLOGY

A primary aim of this study was to document the total symptom experience of ESRD hemodialysis patients including: the factors that influence symptoms, the multidimensional characteristics of symptoms, and the impact of both on QOL. Unique to this research, the level of relief patients obtained from their unpleasant symptoms was a major focus as well. This information was deemed essential to determine if there was a need for improved symptom relief and palliative care in this patient population.

Research Questions

The following research questions were asked to achieve the research objectives:

1. What physiological, psychological, and situational/demographic influencing factors predict the level of symptoms experienced by ESRD hemodialysis patients?

2. What are the characteristics of symptoms reported by ESRD hemodialysis patients in relation to the following symptom dimensions: symptom occurrence (i.e., severity, frequency, duration), symptom distress, and symptom concurrence?

3. What strategies are used by ESRD hemodialysis patients to relieve symptoms?

4. What level of symptom relief is achieved by ESRD hemodialysis patients?

5. What is the relationship between influencing factors and symptoms and the QOL reported by ESRD hemodialysis patients?

6. What is the moderating effect of level of symptom relief on the relationship between symptoms and QOL?

A cross-sectional study design was chosen to answer the research questions. This design permitted the inclusion of a wide variety of patients of varying ages, dialysis histories, and disease severity, resulting in a description of the symptom experience of a diverse group of patients. It was the intent of this study to provide a real-time snapshot of symptom experience, not to document changes over time.

Sample

Patients receiving treatment in two in-center hemodialysis clinics located in Grand Rapids, Michigan were recruited for this study. Both centers are privately owned. At the time of the study approximately 174 patients were being treated at Clinic A. Of those, 77% were White, 20% were Black, and 3% included other groups (e.g., Hispanic, American Indian) (M. Larson, personal communication, June 3, 2003). Clinic B census included 107 patients. Racial mix was nearly 50% Black and 50% White. Only a very small portion of the patients were of other racial origins (R. Ploch, personal communication, August 15, 2003). Both clinics treated patients on a Monday-Wednesday-Friday or Tuesday-Thursday-Saturday schedule. Only Clinic A offered evening dialysis sessions.

Participants recruited for the study had to be at least 21 years of age, alert and oriented, able to understand and speak English, and competent to give informed consent. Ability to read English was not required since measurement instruments were administered via interview. In addition, patients had to be hemodynamically stable at the start of the treatment and remain so throughout the interview. Otherwise, the interview was terminated and completed during the next dialysis session when stable. Nurses supervising the dialysis treatments monitored vital signs at least every hour and more often as necessary.

Children under the age of 21 years were excluded from the study. ESRD is not common in children, less than 0.4% of all dialysis patients in Michigan are below the ag of 20 years (Renal Network of the Upper Midwest, Inc., 2001). In addition, children wh require renal replacement therapy (RRT) are typically treated with peritoneal dialysis or transplantation.

The total convenience sample consisted of 130 patients, ranging in age from 22 t 88 years. Males (51%) and females (49%) were equally represented. The majority of patients were White (69%). Black patients (27%) comprised the largest proportion of those remaining, with only 4% Hispanic and American Indian patients included in the sample. A slight majority of patients were married (52%). Sixty percent attended school for 12 years or less and most were unemployed either because of disability (55%) or retirement (28%). Mean length of time on dialysis was 32.25 months (range 0.42-240 months).

Demographic characteristics of each dialysis clinic are presented in Table 1. The samples differed primarily in regard to race, reflecting their respective clinics. The racia composition of the sample from Clinic A included 84% White, 12% Black, and 4% Hispanic and American Indian participants. Fifty-three percent of the patients from Clin B were Black, 43% were White, and 4% comprised other groups. No significant differences were noted between the samples relative to other demographics including: age, gender, marital status, level of education, employment status, and length of time on dialysis. Forty-eight percent of all patients treated in Clinic A and 44% of the patients dialyzed at Clinic B participated in the study.

The demographics of the sample, with a nearly equal percent of males and females, reflected the in-center hemodialysis population in Michigan with respect to

Table 1

Demographic Characteristics of Patients by Clinic and Total Sample

	Clinic A (*n* = 83)	Clinic B (*n* = 47)	Tot
Characteristic	*n* (%)	*n* (%)	*n* (%
Gender			
Female	42 (51)	21 (45)	63 (4
Male	41 (49)	26 (55)	67 (5
Race			
White	70 (84)	20 (43)	90 (6
Black	10 (12)	25 (53)	35 (2
Hispanic/American Indian	3 (4)	2 (4)	5 (4)
Marital status			
Married	47 (57)	21 (45)	68 (5
Single, never married	6 (7)	9 (19)	15 (1
Divorced/separated	18 (22)	13 (28)	31 (2
Widowed	12 (14)	4 (8)	16 (1
Employment status			
Employed full/part time	11 (13)	2 (4)	13 (1
Retired	26 (31)	10 (21)	36 (2
Disabled	43 (52)	29 (62)	72 (5
Not employed/reason unrelated to health	3 (4)	6 (13)	9 (7)

Table 1 (continued)

	Clinic A (*n* = 83)	Clinic B (*n* = 47)	T
Characteristic	*n* (%)	*n* (%)	*n*
Level of education			
Less than high school	22 (27)	14 (30)	27
High school diploma	26 (31)	16 (34)	42
Some college/vocational school	28 (34)	16 (34)	44
College degree	6 (7)	1 (2)	7
Professional/graduate degree	1 (1)	0	1
Length of time on dialysis in months *M* (*SD*)	27.88 (29.37)	39.96 (42.23)	32.25

gender. Racial mix in Michigan is also evenly distributed; 50% White, 48% Black (Renal Network of the Upper Midwest, Inc., 2001). It was necessary to recruit participants from both clinics to achieve a more representative racial balance.

Because of the Health Insurance Portability and Accountability Act of 1996 (HIPPA), characteristics of those patients who did not participate in the study were not available for comparison. Regulations enacted in April 2003 prior to the beginning of data collection prevented access to private information regarding patients who did not take part in the study (U. S. Department of Health and Human Services [USDHHS], 2003).

Measures

Structured interview questionnaires and a chart review form for laboratory tests were used to collect data relevant to each research question. See Table 2 for a summary of all instruments, including a brief description, scoring, and psychometric properties. Copies of all measures appear in the Appendices.

Influencing Factors: Physiological

Disease severity. The term 'disease severity' was defined as the degree of physiological disturbance present (Craven, Littlefield, Rodin, & Murray, 1991). Determinants of overall physiological disturbance included degree of metabolic homeostasis and the presence of comorbid conditions (Craven et al., 1991). Both were included as indicators of disease severity in the current study.

Metabolic homeostasis was defined as the ability of the body to maintain constancy in the internal environment (Anderson et al., 1998). Of particular interest was the kidney's ability to maintain balance with respect to electrolytes, waste products, and

Table 2

Major Study Variables and Their Measurement

Variable	Measure	Description	Scoring	Psychometrics
Influencing factors: Physiological Metabolic homeostasis	Chemistry Abnormality Score	Based on the results of 13 biochemical tests drawn monthly	▪ K+, BUN, creatinine: normal = 0 abnormal = 1 ▪ All others: normal = 0 mildly abnormal = 1 abnormal = 2 ▪ Score range = 0-23	Validity: content Reliability: Laboratory fully accredited by the College of American Pathologists and the Clinical Laboratory Improvement Act (CLIA)
Comorbid conditions	Demographic questionnaire	List of 14 comorbid conditions	Sum of all comorbid conditions reported	Katz, Chang, Sangha, Fossel, & Bates, 1996
Dialysis adequacy	Biochemical test	Kt/V	Dialyzer clearance x time / volume of body H_20	See above laboratory accreditation
Influencing factors: Psychological Anxiety Depression	Hospital Anxiety and Depression Scale	Assesses both anxiety and depression in physically ill patients. Somatic symptoms are excluded from the scale.	▪ Anxiety subscale; 7 items rated on 0-3 scale; range 0-21 ▪ Depression subscale; 7 items rated on 0-3 scale; range 0-21 normal = 0-7; suggestive = 8-10 probable = 11-21	Validity: content, construct Reliability: Internal consistency (Cronbach's alpha): Full scale = 0.87 Anxiety = 0.84 Depression = 0.79

Table 2 (continued)

Variable	Measure	Description	Scoring	Psychometrics
Influencing factors: Situational/ demographic	Demographic questionnaire	Collects information regarding: age, gender, race, marital status, level of education, length of time on dialysis	NA	NA
Symptoms	Symptoms and Kidney Disease	Assesses 11 physical symptoms associated with ESRD including: severity, frequency, duration, and distress.	▪ Each dimension scored using a 6-point scale ▪ Total symptom score calculated for each symptom by adding score for each dimension ▪ Score range not reported = 0 reported = 4-20	Validity: content Reliability: test-retest total # of symptoms = 0.71 total symptom score = 0.78
Level of symptom relief	Symptom Relief Scale	Assesses strategies used by patients to relieve 11 physical symptoms associated with ESRD; the level of relief achieved overall; satisfaction with relief; relief associated with each symptom dimension including: severity, frequency, duration, distress	▪ Each item scored using 5-point scale ▪ Total relief score; sum of ratings on all items ▪ Relief subscale; sum of ratings on all relief items only ▪ Satisfaction subscale; rating on satisfaction item only	Validity: content Reliability: test-retest Total relief score = 0.47

Table 2 (continued)

Variable	Measure	Description	Scoring	Psychometrics
Performance	Quality of Life	34 items that assess both satisfaction with various aspects of life and the importance of the aspect to the person. Four domains include: health and functioning psychological/spiritual social and economic family	Scoring instructions available from authors. Total score range: 0-30 Subscales scores: 0-30	Validity: content, construct Reliability: Internal consistency (Cronbach's alpha): Full scale = 0.93 Health and functioning = 0.87 Psychological/spiritual = 0.91 Social and economic = 0.75 Family = 0.61

blood components. This variable was measured with the Chemistry Abnormality Score (CAS) (Wolcott & Nissenson, 1988).

The CAS, which was calculated from the results of 11 biochemical tests drawn before dialysis and during the month of participation in the study, provided a summary of ESRD patients' physiological status (Wolcott & Nissenson, 1988). The tool used to compute the CAS includes a listing of the 13 laboratory tests and values that are considered normal, mildly abnormal, and abnormal. Hematocrit, serum glutamic-pyruvic transaminase (SGPT), serum glutamic-oxaloacetic transaminase (SGOT), alkaline phosphotase, total protein, albumin, triglycerides, carbon dioxide, calcium, and phosphorus are scored as normal (0), mildly abnormal (1), or abnormal (2). Three of the variables (i.e., potassium, blood urea nitrogen, creatinine) are scored as normal = 0 or abnormal = 1. The potential range of CAS scores is 0 – 23, with higher scores indicative of more abnormal physiological status. Because triglyceride and SGPT levels are not routinely assessed in patients treated at the two clinics used for data collection, the possible range of CAS scores for this study was 1 – 19.

In developing the CAS, the investigators used a modified Delphi approach to determine which laboratory values to include in the scoring as well as the criterion values and the cut-off points for abnormality in the ESRD population (A. Nissenson, personal communication, April 14, 2003). The Delphi method was first developed by scientists at the Rand Corporation as an iterative, consensus building process for predicting future events. The strategy has since been applied in a variety of fields to develop consensus and make group decisions (Custer, Scarcella, & Stewart, 1999).

The Delphi technique is described as an exercise in group communication among geographically dispersed experts in a field who share the same interests. Three key elements of the process include: a structured information flow, feedback to the participants, and participant anonymity (Nelson, 2002). In a modified Delphi approach, the process begins with a set of items carefully selected from the literature and expert opinion. In subsequent rounds, the experts suggest modifications based on feedback from the previous round. Through a series of rounds the process is designed to yield consensus (Custer et al., 1999).

Laboratory tests and criterion values included in calculation of the CAS were chosen by consensus as described above. In addition, the laboratory tests assessed are those routinely performed on hemodialysis patients monthly. Both the method of development and use of commonly assessed laboratory tests contribute to the content validity of the CAS (Wolcott & Nissenson, 1988). Internal consistency reliability of the CAS was not assessed in this or previous studies because doing so was not warranted conceptually.

However, the accuracy and precision with which biochemical tests are performed must be addressed. Laboratories that run the monthly blood studies for the dialysis clinics involved in this study are fully accredited by the College of American Pathologists (CAP) (B. DeVries, personal communication, January 8, 2004). The CAP is approved as an accrediting organization for clinical laboratories under the Clinical Laboratory Improvement Amendments of 1988 (CLIA) program (CLIA Program; Approval of the College of American Pathologists, 1995). The CAP has established performance standards related to all areas of laboratory functioning that must be met for accreditation. Accreditation acknowledges adherence to these standards (CAP, 2004).

The presence of comorbid conditions was also included as a component of disease severity in the ESRD population. Comorbidity was defined as a significant concurrent disease in addition to ESRD which involves organs other than the kidneys but which may also be responsible for kidney failure (Khan 1998).

Comorbid conditions were measured using a demographic questionnaire that included a list of commonly occurring concurrent diseases. The conditions chosen for the list were adapted from a comorbidity questionnaire developed by Katz, Chang, Sangha, Fossel, and Bates (1996). Katz et al. modeled their measure on the Charlson Comorbidity Index, an extensively validated chart review instrument (Charlson, Pompei, Alex, & MacKenzie, 1987; Katz et al., 1996). In addition, several of the comorbidities inventoried in this study are also requested by the Medical Evidence Report Form which is completed by dialysis facilities at the initiation of dialysis (USDHHS, 2004).

However, hypertension was notably absent from the tool developed by Katz et al. (1996). Along with diabetes, high blood pressure is one of the most common complicating conditions present in new dialysis patients (USRDS, 2001). Hypertension was added to the list for this reason. The final list presented to patients included the following comorbidities: heart attack, heart failure, clogged arteries in the legs, numbness in feet/legs, stroke, chronic lung disease, stomach ulcer/reflux disease, diabetes, arthritis, lupus, fibromyalgia, cirrhosis of the liver, cancer, and hypertension.

Patients were asked which of the conditions on the list they had been told by a health professional that they currently experience. Data about comorbidities were collected via self-report because this method has been found to be valid, reliable, and to correlate with more expensive chart audits (Katz et al., 1996). Patients were also allowed to report comorbidities in addition to those listed. A comorbidity score was calculated by summing the total number of conditions reported from the original list. Additions made by patients to the list were not included in the scoring.

Dialysis adequacy. Dialysis adequacy was a second major physiological influencing factor included in this study. It was defined as the effectiveness with which dialysis treatment removes waste products from the body, specifically urea (National Institute of Diabetes and Digestive and Kidney Disases [NIDDK], 2001). Dialysis adequacy was measured using the most recently reported Kt/V (i.e., dialyzer clearance of urea x time / volume of body water) levels found in patients' charts. Kt/V is determined by comparing levels of urea in blood drawn at the beginning and at the end of a dialysis session. Typically, Kt/V is evaluated monthly. A minimum value of 1.2 is desired (NKF, 1997).

Influencing Factors: Psychological

Anxiety and depression represented the psychological influencing factors in this study. Anxiety was defined as a state in which the individual experiences feelings of uneasiness and activation of the autonomic nervous system in response to a vague, nonspecific threat (Carpenito, 1997). Depression was defined as the loss of pleasure response (i.e., anhedonia); namely, the state of reduced ability to experience pleasure (Snaith, 2003).

The Hospital Anxiety and Depression Scale (HADS) was used to measure the presence and severity of both anxiety and depression. The HADS was originally used in the hospital setting with patients 16 to 65 years of age as a screening tool for the detection of clinically significant anxiety and depression (Zigmond & Snaith, 1983).

Subsequent studies have shown the scale to be valid for use in outpatient and community sites as well as with the elderly (Aylard, Gooding, McKenna, & Snaith, 1987; Flint & Rifat, 2002; Snaith & Zigmond, 1994; Watts et al., 2002). Because the HADS was developed for use with physically ill patients, scale items that may be symptomatic of both physical illness and anxiety and depression were excluded. This makes the tool especially useful for assessment of ESRD patients who manifest symptoms that might give misleading scores on other anxiety and depression scales. A number of researchers have used the tool to assess mood disturbances in the ESRD population for this reason (Killingworth & Van Den Akker, 1996; Lye, Chan, Leong, & van der Straaten, 1997; McCann & Boore, 2000).

The HADS is comprised of a total of 14 items; 7 evaluate anxiety and 7 assess depression. Patients respond using a 4-point numeric rating depending on the severity of the problem described in each question. Response bias is avoided by alternating the order of responses so that for some of the items the first response indicates maximum severity and in others it is the last. In addition, four response choices are included as options to prevent patients from consistently choosing the middle choice. Items on each of the subscales are summed, with possible scores ranging from 0-21. A score below 8 is in the normal range, 8-10 suggests of the presence of the respective state, and greater than 10 indicates probable disorder (Zigmond & Snaith, 1983).

Construct validity was assessed during instrument development by comparing the HADS scores with a formal psychiatric assessment. Correlations between the psychiatric evaluations and the subscale scores were high for both anxiety ($r = 0.70, p < 0.001$) and depression ($r = 0.74, p < 0.001$) (Zigmond & Snaith, 1983). The HADS was also validated against the Irritability-Depression-Anxiety scale, a tool used to measure these mood disorders in a variety of settings (Aylard et al., 1987). In addition, an exploratory factor analysis of the HADS was carried out in a study of 568 patients with cancer (Moorey, et al., 1991). Two distinct but correlated factors emerged that corresponded to the questionnaire's anxiety and depression subscales.

Internal consistency reliability was examined in preliminary studies of the tool (Zigmond & Snaith, 1983). For the anxiety subscale, inter-item correlations ranged from 0.41 to 0.76. The items in the depression scale had correlations ranging from 0.30 to 0.60. Further assessment of reliability by Moorey et al. (1991) revealed a Cronbach's alpha of 0.93 for the anxiety scale and 0.90 for the depression scale. For this study, evaluation of the internal consistency reliability for the full scale resulted in a Cronbach's alpha of 0.87 (n = 129). A Cronbach's alpha of 0.84 was found for the anxiety subscale and 0.79 for the depression subscale.

Influencing Factors: Situational/Demographic

Situational/demographic influencing factors referred to aspects of the social and physical environment that may affect symptoms including: age, gender, race, marital status, level of education, and length of time on dialysis (Lenz et al., 1997). These variables were measured using a demographic questionnaire designed by the investigator.

Age was reported in years and length of time on dialysis was reported in months. Racial categories included: African American or Black, Hispanic or Latino, Native American or American Indian, Asian or Pacific Islander, White non Hispanic, or other. Married, living with husband/wife; single, never married; divorced/separated; or widowed were options available for marital status. Level of education was ranked as 8th grade or less, some high school, high school diploma or GED, vocational school or some college, college degree, or professional/graduate degree.

Symptoms

Symptoms were defined for this study as multidimensional phenomena characterized by their occurrence, distress, and concurrence. Occurrence included the symptom's severity (intensity), frequency (how often the event occurs within a given time frame), and duration (how long it lasts) (McDaniel & Rhodes, 1995). The degree of bother or physical/emotional upset associated with a symptom defined distress (Rhodes & Watson, 1987). The final symptom dimension, concurrence described the coexistence and interaction of multiple symptoms (Lenz et al., 1997).

All symptom dimensions were measured using a disease specific physical symptom tool developed for ESRD patients by Parfrey et al. (1988; 1989). This tool was chosen because it taps several symptom dimensions. However, the original tool was adapted in consultation with Parfrey (personal communication, April 29, 2003) to include all symptom dimensions of interest to the current study. Since distress was not assessed in the original instrument, items that questioned the impact of the symptom on QOL and activities of daily living were changed to assess this dimension. In addition, response sets for the duration and frequency items were changed from yes/no ratings to an ordinal scale. The current form of the tool assesses the severity, frequency, duration, and distress associated with the same 11 symptoms included in the earlier tool developed by Parfrey and colleagues (1988) and commonly experienced by hemodialysis patients. The physical symptoms assessed included: tiredness, itching, headaches, problems sleeping, joint pain, cramps, shortness of breath, chest pain, nausea and/or vomiting, abdominal pain, and muscle weakness. An 'other' category is also included for reporting symptoms experienced, but not among those listed.

Patients were asked to rate each symptom dimension using a 5-point numeric rating scale; namely, severity (1 = not at all severe to 5 = very severe), frequency (1 = not often to 5 = every day), duration (1 = not long to 5 = all day), and distress (1 = a little to 5 = very severely). An aggregate score was calculated for each symptom by summing ratings on each of the symptom dimensions. The aggregate symptom score was 0 if the patient did not report the symptom and ranged from 4 to 20 if the patient did report the symptom. Higher scores correspond to higher levels of the symptom.

Content validity was established for the original tool developed by Parfrey et al. (1988; 1989) through patient interviews, literature review, and expert opinion. Since the symptoms included in the adapted tool are identical to those in the original tool, it has content validity. In addition to Parfrey, a draft of the tool was reviewed by two nurses who are experts in the field of nephrology nursing. Anita Molzahn is a well known researcher specializing in QOL issues. She is a professor in the School of Nursing as well as Dean of Human and Social Development at the University of Victoria, British Columbia. Therese Winslow is a clinician who has worked with both hemodialysis and renal transplant patients for over 30 years. She is employed at St. Mary's Mercy Medical, Grand Rapids, Michigan, which is the regional kidney center for West Michigan. No significant changes were made in the tool following feedback.

Reliability was evaluated during the course of the study. Approximately every fifth participant enrolled (*n* = 24) completed the tool on two occasions one week apart and on the same day of the week. The total symptom scores for the two administrations were highly correlated ($r = 0.78, p \leq 0.01$). Likewise, the total number of symptoms reported the first time was highly correlated with the number reported the second ($r = 0.71, p \leq 0.01$). The instrument demonstrated strong test-retest reliability. Also, paired sample t-tests demonstrated that there were no significant differences between symptom scores ($t(23) = 0.12, p = 0.91$) or total numbers of symptoms ($t(23) = -0.54$, $p = 0.59$) reported at Time 1 and Time 2.

Level of Symptom Relief

Level of symptom relief was defined by three components: the strategies used to obtain relief from symptoms, the degree to which symptoms were relieved, and the satisfaction with the degree of relief achieved. Symptom relief strategies were defined as the methods used by patients to achieve a level of symptom relief. Strategies included those that were prescribed by healthcare professionals as well as any that were self-initiated. Degree of relief was defined as a subjective evaluation of the extent to which symptoms were relieved. Perceived satisfaction with relief was the extent to which the individual was content with current level of symptom relief.

A review of the literature revealed no existing tool to measure either the level of symptom relief or the relief strategies used by hemodialysis patients. Therefore, an instrument was developed specifically for the study to assess these variables. The tool was designed to correspond to the symptom measure previously described in order to assess the level of relief obtained from each of the reported symptoms.

The instrument is comprised of two parts: strategies used to relieve symptoms and the level of relief achieved. Part 1 of the tool lists strategies commonly used to relieve each of the symptoms, including those prescribed by healthcare providers as well as self-initiated methods. Patients are asked to indicate which of the listed strategies are used as well as the one that they perceive as the most effective in relieving each of the symptoms. An 'other' category is included for patients to report strategies used in addition to those listed. This part of the tool obtains descriptive data regarding methods of symptom relief.

Part 2 of the tool evaluates the degree of relief obtained using the methods identified in Part 1. Patients respond to a general question regarding their level of relief using the following 6-point numeric rating scale: 0 = no relief to 5 = complete relief. Patients are also questioned as to their degree of satisfaction with the relief they obtain from symptoms. Responses range from 0 to 5; 'not at all satisfied' to 'completely satisfied.' In addition, patients are asked to indicate whether their actions decreased each dimension individually using a 6-point numeric scale to rate each dimension; 0 (not at all) to 5 (very much).

The tool results in three scores for each of the 11 symptoms: an aggregate symptom relief score, a relief subscale score, and a satisfaction subscale score. A total relief score is calculated for each symptom by adding: (a) the rating given on the general relief question, (b) the rating on the satisfaction with relief question, and (c) the ratings given for relief relative to each of the symptom dimensions. Possible scores range from 0 to 30. The satisfaction subscale score is the rating given on the satisfaction item only (range = 0-5). A relief subscale score is calculated from all items minus the satisfaction question (range = 0-25). In all cases, higher scores are indicative of a higher level of relief achieved.

Content validity is supported by the literature of common symptom management techniques (Ferrell & Coyle, 2001). This measure was also reviewed by the same experts in nephrology nursing who reviewed the symptom tool. As with the symptom tool, 24 patients completed this instrument twice, one week apart on the same dialysis day. Test-retest reliability was only moderate ($r = 0.47, p \leq 0.05$). However, there was not a significant difference found between total symptom relief scores at Time 1 and Time 2 ($t(23) = 0.18, p = 0.86$).

Performance: Quality of Life

The consequence of interest to this study was the QOL of hemodialysis patients. QOL was defined as a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her (Ferrans & Powers, 1992, p. 29).

The Ferrans and Powers (1985) Quality of Life Index—Dialysis Version (QLI) was used to measure QOL. The QLI is a two part, self-report questionnaire that assesses both satisfaction with various aspects of life and the importance of each aspect of life to the person (Ferrans & Powers, 1985). Each part is composed of a total of 32 items that evaluate the following four domains: health and functioning, psychological/spiritual, social and economic, and family. In addition, the hemodialysis version includes two additional items related to dialysis treatment.

Participants respond to statements using a 6-point numeric rating scale ranging from 'very dissatisfied' to 'very satisfied' for the satisfaction items and from 'very unimportant' to 'very important' for the importance items. Scoring the QLI involves centering and weighting of scores. The step-by-step scoring instructions, which include a computer program written for use with SPSS, were used to score the QLI in this study.

These instructions are available from the authors on their website (Ferrans, 2004). The tool yields a total score as well as four subscale scores corresponding to the domains of life assessed. Potential scores for both the subscales and total score range from 0-30, with higher scores indicative of higher QOL.

An advantage of the QLI is that it is constructed in a manner that prevents problems with collinearity among the study variables. Unlike other QOL instruments, the QLI does not include a symptom scale. Energy is the only symptom that is assessed using two items. One item questions the importance of having enough energy for everyday activities. A second asks about the level of satisfaction with the amount of energy actually present. It does not evaluate symptom dimensions.

Similarly, although the patients' marital status is examined on both the demographic questionnaire and the QLI, the questions on each tap different concepts. Patients are asked to indicate which marital status category they belong to on the demographic questionnaire. In contrast, questions related to marital status included on the QLI assess the status of the relationship not the category to which the patient belongs. To validate the absence of collinearity, the tolerance associated with marital status was examined when QLI scores were regressed on the demographic/situational influencing factors. A tolerance of 0.84 indicated that marital status was independent of other variables (George & Mallery, 2003).

The validity of the QLI has been established. Content validity has been supported by the fact that items included on the tool were based on an extensive review of the QOL literature as well as patients' ideas regarding the characteristics of a quality life (Ferrans & Powers, 1985). Further support for content validity was provided by an acceptably high rating using the Content Validity Index (Oleson, 1990).

Construct validity of the QLI was established through factor analysis. The factor analysis solution, which revealed the four domains of QOL listed previously, accounted for 91% of the total variance. Factor analysis of the four primary factors also revealed one higher order factor, representing QOL (Ferrans & Powers, 1992). The contrasted group approach was also used to support construct validity. Participants were divided into groups based on self-reported levels of pain, depression, and coping skills. Those who were more depressed, exhibited higher levels of pain, and coping less well also reported lower QOL (Ferrans, 1990). The QLI was also compared with other similar instruments to establish convergent validity. For example, strong correlations were found between the total QLI score and Campbell, Converse, and Rodger's measure of life satisfaction (Ferrans & Powers, 1985).

Both internal consistency and temporal reliability have been established. Internal consistency reliability has been evaluated with several groups. However, of interest to this study were findings specific to the dialysis population. Cronbach's alphas for the total QLI in studies with dialysis patients have ranged from 0.90 to 0.93. Internal consistency reliability was established for the subscales in one study with dialysis patients with the following results: health and functioning 0.87, psychological/spiritual 0.90, social and economic 0.82, and family 0.77 (Ferrans & Powers, 1992). Test-retest reliability has also been demonstrated in studies that spanned a 2 to 4 week interval (Ferrans & Powers, 1985).

The tool was also found to be sensitive to change, with QLI scores changing significantly over time following an intervention (Ferrans & Powers, 1992). This property will be of importance to future studies that evaluate the impact of interventions on symptom experience and QOL. Finally, this tool was an appropriate QOL measure because it was written at a fourth grade level and has been tested for use with racial and cultural groups sampled for this study (Ferrans, 1997).

Internal consistency reliability of the QLI was evaluated for this study. The Cronbach's alpha for the entire QLI was 0.93. Cronbach's alphas were also computed for the subscales with the following results: health and functioning 0.87, psychological/spiritual 0.91, social and economic 0.75, and family 0.61. Reliabilities were assessed with the full sample of 130 patients. The moderate value noted for the family subscale is comparable with previous reports that have consistently noted the lowest alpha for this subscale (Deshotels, Planchock, Dech, & Prevost, 1995; Ferrans, 1990; Ferrans & Powers, 1992).

Procedures

The study was approved by the Michigan State University Committee for Research Involving Human Subjects (UCRIHS) as well as the review boards of both dialysis clinics. In light of HIPPA regulations enacted prior to the beginning of data collection, no contact with patients was allowed without prior written consent. Therefore, staff nurses in both clinics were required to obtain a pre-consent using a form approved by UCRIHS and both clinic review boards. Registered nurses and technicians from each of the dialysis units were introduced to the study as well as their role in obtaining pre-consents at a meeting held prior to beginning of data collection. Following this orientation, nurses approached patients as time allowed and explained only that a research study was being conducted and that the investigator was requesting permission to introduce herself and explain the study. Patients were assured that signing the pre-consent did not obligate them to participate once the study had been explained.

Once pre-consent was obtained, each patient was approached individually, introduced to the study, and asked to participate if he/she met the inclusion criteria. Of patients who signed pre-consent forms, only three individuals elected not to participate after the study was explained. These patients stated that they were either too tired to participate or were not interested. Written informed consent was obtained from those who agreed to participate after the study was explained. Percentage of participation from each clinic was moderate; 48% of the patients treated at Clinic A and 44% of those receiving dialysis at Clinic B completed interviews. Due to privacy laws, no information was available about those patients who declined to sign pre-consent forms or agree to participate in the study.

Patients were interviewed immediately after obtaining informed consent. Although patients were given the option of completing the interview in a private room rather than in their dialysis chairs in the open unit, none desired to do so. Hemodialysis sessions typically required from 3 to 4 hours. Only approximately the first ½ hour and last ½ hour were occupied with activities involved in initiating and completing treatment. Interviewers were not allowed in the vicinity of the dialysis chairs during those times. During the remaining time, however, patients were free to engage in sedentary activities such as talking.

All questionnaires were administered via interview to maintain uniformity of administration. This was a necessity since the majority of patients found it difficult to write due the need to keep their arms still for dialysis and blood pressure monitoring.

Many were also not able to see or write well enough to complete the measures unaided.

Patients were interviewed on three shifts, usually during the periods from 8:00 a.m. to 11:30 a.m., 12:30 p.m. to 3:30 p.m., and 5:00 p.m. to 8:00 p.m. Interviews required from ½ hour to 2 hours, with an average of 45 minutes, depending on the number of symptoms patients reported. Only one interview was not completed in one session due to a hypotensive episode experienced during the dialysis treatment. All of the questionnaires but the QLI were finished prior to the onset of low blood pressure, at which time the interview was terminated. The QLI was completed during the next dialysis session. No further problems arose during completion of the interview. No patients refused or failed to complete the entire interview. No patients experienced undue fatigue during the interview and many expressed appreciation for the chance to talk about their symptoms.

Interviews were conducted by the primary investigator (76%) and two research assistants (24%). Upon hire, research assistants were oriented to the purpose of the study, privacy issues, and their job responsibilities. All interviewers also completed the tutorial provided by the National Institute of Health regarding the rights of human subjects. They observed from one to three interviews prior to conducting their first. They were also instructed in completing the CAS. Once data were entered into the computer database, one of the research assistants rechecked all entries for accuracy.

Protection of Human Subjects

Additional precautions were taken to protect participants' confidentiality during the course of the study. All information obtained from the patients and their medical records was identified by respondent number only. No names appeared on any of the questionnaires completed by patients. A master list of participants and their identification numbers is being kept on a disc in a locked disc box. All consent forms are being stored in a locked file separate from the interview questionnaires. All participant files are being stored in a fire-proof locked file cabinet. There is no link between the master list and the database. All data generated from this study will be kept in a locked file cabinet for a period of three years following completion of the study. A copy of the original database as well as information regarding location of the data will be kept on file in the College of Nursing Research and Doctoral Program office at Michigan State University for that period of time as well.

Data Analysis

Sample demographics. Demographic characteristics of the sample were analyzed using descriptive statistics including frequencies, measures of central tendency, and measures of variability. This analysis included age, gender, race, marital status, level of education, length of time on dialysis as well as physical and mental health characteristics of the sample.

Research questions. The research questions were analyzed in the following manner:

Question 1: What physiological, psychological, and situational/demographic influencing factors predict the level of symptoms experienced by ESRD hemodialysis patients?

Analysis: Regression analysis was employed to determine which influencing factors predicted symptom scores. Each category of influencing factors was entered into the analysis beginning with situational/demographic variables followed by psychological and physiological. Nonsignificant variables with p values 0.50 were trimmed from the model at each step of the analysis.

Question 2. What are the characteristics of symptoms reported by ESRD hemodialysis patients in relation to the following symptom dimensions: symptom occurrence (i.e., severity, frequency, duration), symptom distress, and symptom concurrence?

Analysis: Frequency distributions and descriptive statistics were employed to examine the symptom dimensions of severity, frequency, and duration. An exploratory factor analysis was performed to analyze symptom concurrence.

Question 3. What strategies are used by ESRD hemodialysis patients to relieve symptoms?

Analysis: The methods used by patients to relieve their symptoms were examined using descriptive statistics: frequencies and percentages.

Question 4. What level of symptom relief is achieved by ESRD hemodialysis patients?

Analysis: Descriptive statistics were employed to answer this research question, including measures of central tendency and variability.

Question 5. What is the relationship between influencing factors and symptoms and the QOL reported by ESRD hemodialysis patients?

Analysis: Correlation and regression analysis was used to explore the relationship between influencing factors and symptoms and QOL. A series of regression analyses were conducted to determine significant predictors of QOL. Each category of influencing factors was entered into the regression beginning with situational/demographic followed by psychological and physiological. Again, nonsignificant variables with p values 0.50 were removed from the model at each step. Symptom scores were added to the regression analysis after influencing factors.

Question 6. What is the moderating effect of level of symptom relief on the relationship between symptoms and QOL?

Analysis: This research question was analyzed using regression analysis including: all variables retained in the model following analysis of Question 5, level of relief, and the interaction of symptoms and level of relief. As Aiken and West (1991) suggest, both symptoms and level of symptom relief were centered around group means. The moderating effect of level of relief on the relationship between symptoms and QOL was tested with the interaction term.

Chapter 4

RESULTS

Descriptive statistics for each component of the study model will be presented first, followed by results that address each of the research questions. Descriptive statistics for level of relief will be included with the discussion of the research question that addresses that component of the model. All analysis were done using SPSS 10.0 version.

Influencing Factors: Physiological

Disease severity. The hemodialysis patients in this sample maintained adequate physiologic balance with the exception of phosphorus (*M* = 5.74 mg/dl, *SD* = 1.75) and alkaline phosphatase (*M*= 122.37 U/L, *SD* = 77.10). See Table 3 for results of all laboratory tests and acceptable levels for ESRD patients (Good Samaritan Hospital Chronic Dialysis Center, 2004). Further evidence of biochemical stability was provided by low CAS scores, *M* = 1.84, *SD* = 1.49 (possible range 0-19).

Patients reported an average of four comorbid conditions. High blood pressure was by far the most prevalent concurrent illness, reported by 82% of the sample. Peripheral neuropathy (49%), stomach ulcers/reflux (48%), arthritis (46%), and diabetes (46%) rounded out the top five comorbidites in descending order of occurrence. See Table 4 for the frequency of all 14 comorbid conditions listed on the demographic questionnaire.

Dialysis adequacy. Patients also received an adequate dose of dialysis according to the National Kidney Foundation (NKF) (1997) Clinical Practice Guidelines. Mean Kt/V (dialyzer clearance of urea x time / volume of body water) values were above the level recommended (*M* = 1.55 ml/min, *SD* = 0.35). The established benchmark for dialysis adequacy is a Kt/V $\geq$ 1.2 ml/min (NKF, 1997). Values at or above this standard

Table 3

Physical and Mental Health Characteristics of Sample

Characteristic	*M* (*SD*)	Normal value	Acceptable ESRD normal
Laboratory values (pre-dialysis)			
Potassium (meq/L)	4.89 (0.63)	3.5-5.4	4.0-6.5
Creatinine (mg/dl)—male	9.39 (2.80)	0.5-1.1	10-20
Creatinine (mg/dl)—female	8.58 (2.74)	0.6-1.2	10-20
Blood urea nitrogen (mg/dl)	60.47 (18.08)	7-25	40-85
Hematocrit (%)—male	37.10 (3.74)	40-54	30-36
Hematocrit (%)—female	37.36 (4.56)	37-47	30-36
Alkaline phosphatase (U/L)	122.37(77.10)	30-115	30-115
Albumin (g/dl)	3.84 (0.40)	3.5-5.5	3.8
Calcium (mg/dl)	9.22 (0.89)	8.5-10.8	8.5-10.8
Phosphorus (mg/dl)	5.74 (1.75)	2.5-4.5	3.5-5.5
CAS	1.84 (1.49)	NA	NA
Number of comorbid conditions	4.29 (1.95)	NA	NA
Dialysis adequacy (Kt/V)	1.55 (0.35)	NA	1.2
HADS—anxiety	5.95 (4.76)	7	7
HADS—depression	5.66 (4.03)	7	7

Note. NA = not applicable; HADS = Hospital Anxiety and Depression Scale; CAS = Chemistry Abnormality Score; Kt/V = dialyzer clearance x time / volume of body water (approximately 60% of body weight).

Table 4

Prevalence of Self-Reported Comorbid Conditions

Condition	*n*	%
High blood pressure	106	82
Numbness in feet/legs	63	49
Stomach ulcer/reflux disease	62	48
Arthritis	60	46
Diabetes	60	46
Heart failure	55	42
Heart attack	45	35
Clogged arteries in legs	32	25
Cancer	27	21
Chronic lung disease	22	17
Stroke	18	14
Lupus	5	4
Fibromyalgia	2	2
Cirrhosis	0	0

meet the NKF guidelines for adequacy.

Influencing Factors: Psychological

Anxiety and depression. Scores on the anxiety subscale of the HADS varied considerably (*range* = 0-21). However, the average anxiety score was within the normal range ($M = 5.95$, $SD = 4.76$). Depression scores also varied across individuals (*range* = 0-19). The mean depression score was 5.66 ($SD = 4.03$), also within normal limits.

Breaking down the anxiety scores by category, 68% of the patients' scores fell in the normal range (0-7), 12% in the range suggestive of the disorder (8-10), and 20% in the probable range ($\geq$ 11). Depression scores were categorized as follows: 70% normal (0-7), 18% possible presence of the disorder (8-10), and 12% probable presence of depression ($\geq$ 11).

Influencing Factors: Situational/demographic

Age. Patients ranged in age from 22 to 88 years of age, with a mean of 60.22 years ($SD = 32.25$).

Gender. The sample was evenly divided by male and female.

Race. Racial composition of the full sample was 69% White, non Hispanic; 27% Black; and 4% other racial minorities. When the two dialysis clinics were examined separately, the racial make-up of the sample from Clinic A was 84% White and 12% Black. The sample from Clinic B included a greater percentage of minority patients (i.e., 53% Black, 43% White).

Marital status. The majority of patients were married, living with a spouse (52%). The second largest category included patients who were divorced or separated (24%). The final 24% was comprised of individuals who were widowed or had never been married.

Level of education. Educational achievement varied, but 72% of the sample graduated from high school at a minimum. Only 8% had eighth grade or less education.

Length of time on dialysis. Mean and median length of time on hemodialysis were 32.25 months and 20 months, respectively. There was wide variability noted in treatment duration, with a range of 0.42 months to 20 years. Fifty-nine percent of the patients had been on dialysis for 2 years or less, only 3% had been treated for more than 10 years.

Symptoms

Patients reported an average of 5.67 symptoms. Tiredness, the most prevalent of the 11 physical symptoms assessed, was experienced by 77% of the sample. Following close behind were problems sleeping, which were report by 63% of the patients. Least commonly occurring was chest pain. In addition to those listed, two symptoms frequently reported in the ‘other’ category were numbness/tingling in the hands and feet (49%) and restless legs (22%). See Table 5 for the prevalence of all 11 symptoms assessed in addition to others not listed but reported by at least 10 patients.

Level of Relief

Descriptive statistics for level of relief will be discussed in relation to research question number 4.

Quality of Life

Total scores for the QLI ranged from 7.02 to 29.22, with a mean of 20.76 (*SD* = 5.06). The mean score for the family subscale was the highest at 24.68 (*SD* = 5.59), followed by the psychological/spiritual subscale (*M* = 22.40, *SD* = 6.55) and the social and economic subscale (*M* = 22.17, *SD* = 5.35). Mean scores for the health and

Table 5

Prevalence of Symptoms Reported by ESRD Hemodialysis Patients

Symptom	*n*	%
Tiredness	100	77
Problems sleeping	82	63
Cramps	68	52
Muscle weakness	67	51
Joint pain	63	48
Itching	56	43
Shortness of breath	43	33
Nausea / vomiting	41	32
Headaches	39	30
Abdominal pain	18	14
Chest pain	17	13
Others*		
Numbness / tingling in hands, feet	64	49
Restless legs	29	22
Changes in taste / smell	14	11
Decreased appetite	12	9
Other pain	10	8

Note. * Symptoms reported in the "other" category of the symptom tool by at least 10 patients functioning subscale were the lowest ($M = 17.88$, $SD = 5.89$). The possible range of scores is 0-30 for the total QLI and subscales, with higher scores indicative of better QOL.

Research Questions

The remaining results of the study are presented according to the research questions posed.

Question 1: What physiological, psychological, and situational/demographic influencing factors predict the level of symptoms experienced by ESRD hemodialysis patients? Prior to conducting regression analysis, a total symptom score was calculated for each participant by summing the scores received for all of the symptoms reported by the individual. This value was used in all regression analyses with symptoms as the dependent variable. Correlations between predictor variables and symptom scores were also calculated. A series of regression analyses were then conducted to evaluate which of the influencing factors included in the study model were significant predictors of symptoms.

The influence of situational/demographic influencing factors (i.e., age, gender, race, marital status, level of education, and length of time on dialysis) on symptom scores was examined first. The correlations among these predictor variables were generally low (see Table 6). The only significant correlations were seen between age and race ($r = -0.32$, $p < 0.01$), age and level of education ($r = -0.32$, $p < 0.01$), and race and marital status($r = -0.20$, $p < 0.05$). A greater number of older patients were White. Older participants also had less education. White patients were more often married than non-White patients. Age was the only situational/demographic predictor that was

Table 6

Correlations Among Situational/Demographic, Psychological, and Physiological Influencing Factors

	Age	Gender	Race	Marital status	Educ	Time on dialysis	Anxiety	Depress	Lab values	Comorbid conditions	Dialysis adequacy
Age	--	-0.05	-0.32**	0.14	-0.32**	-0.04	-0.43**	-0.17*	-0.23**	0.03	0.17
Gender		--	0.05	-0.15	0.04	-0.09	0.15	-0.15	0.05	0.08	0.27**
Race			--	-0.20*	-0.06	0.17	0.05	-0.09	-0.01	-0.11	0.08
Mar status				--	0.10	-0.05	-0.14	-0.10	-0.20*	-0.17*	-0.12
Educ					--	-0.03	0.02	-0.03	0.08	-0.09	-0.17
Time on dialysis						--	-0.13	-0.07	0.00	-0.11	0.06
Anxiety							--	0.53**	0.24**	0.03	-0.05
Depress								--	0.17*	0.17	-0.10
Lab values									--	0.13	0.00
Comorbid										--	-0.06
Dialysis adequacy											--

Note. * $p < 0.05$, ** $p < 0.01$

significantly correlated with symptom scores ($r = -0.29, p < 0.01$), indicating that older patients had lower symptom scores than younger dialysis patients.

Symptom scores were regressed on all situational/demographic influencing factors. See Table 7 for a summary of regression 1 with symptom score as the dependent variable. Analysis revealed $R^2 = 0.17$, $F(6,123) = 4.06$, $MSE = 1088.22$, $p = 0.00$. Age and race were significant predictors of symptoms. Marital status and length of time on dialysis were trimmed from the model because they did not contribute any unique variance to symptoms and were nonsignificant at a $p \geq 0.50$. Gender and level of education were retained in the model due to parameter estimates that neared significance.

Psychological influencing factors were added to the model in the next step of the analysis. Correlations among the situational/demographic predictor variables, anxiety, and depression are provided in Table 6. Age was negatively correlated with anxiety ($r = -0.43, p < 0.01$) and depression ($r = -0.17, p < 0.05$) as well as with symptom scores ($r = -0.29, p < 0.01$). Reporting less anxiety and depression, older patients also reported lower levels of symptoms. Not surprisingly, anxiety and depression were moderately and positively correlated with each other as well as with symptom scores.

See regression 2 on Table 7 for a summary of the regression analysis adding the psychological influencing factors to the model. Forty-one percent of the variance in symptoms was accounted for in this step, $R^2 = 0.41$, $F(6,122) = 14.23$, $MSE = 772.57$, $p = 0.00$. Anxiety and depression contributed significantly to the model, adding 24% of the variance. Race was also a significant predictor of symptom scores.

The last category of influencing factors was then added to the model. Physiological factors included Chemistry Abnormality Scores (CAS), comorbid conditions, and adequacy

Table 7

Summary of Regression Equations Identifying Predictors of Symptoms

Regression	Independent variables	R^2	B	SE	β	*t*	*p*
1	Influencing factors: situational/ demographic	0.17					
	Age		-0.92	0.21	-0.41	-4.32	0.000
	Gender		9.48	5.90	0.14	1.61	0.111
	Race		-19.58	6.89	-0.26	-2.84	0.005
	Marital status		-2.55	6.06	-0.04	-0.42	0.675
	Level of education		-5.10	2.97	-0.15	-1.72	0.089
	Time on dialysis		0.01	0.09	0.01	0.12	0.904
2	Influencing factors: trimmed situational/ demographic, psychological	0.41					
	Age		-0.37	0.20	-0.16	-1.82	0.071
	Gender		9.46	5.15	0.13	1.84	0.069
	Race		-12.14	5.88	-0.16	-2.06	0.041
	Level of education		-2.46	2.55	-0.07	-0.97	0.337
	Anxiety		2.47	0.70	0.33	3.56	0.001
	Depression		2.54	0.75	0.29	3.38	0.001
3	Influencing factors: trimmed situational/ demographic, psychological, physiological	0.50					
	Age		-0.28	0.20	-0.12	-1.37	0.175
	Gender		5.42	5.35	0.08	1.01	0.314
	Race		-6.31	5.84	-0.08	-1.08	0.283
	Level of education		0.22	2.55	0.01	0.09	0.930
	Anxiety		2.83	0.69	0.38	4.09	0.000
	Depression		1.79	0.76	0.21	2.36	0.020
	CAS		-0.07	1.83	-0.00	-0.04	0.968
	Comorbid conditions		5.57	1.28	0.31	4.34	0.000
	Dialysis adequacy		-4.79	7.33	-0.05	-0.65	0.515

Table 7 (continued)

Regression	Independent variables	R^2	B	SE	β	*t*	*p*
4	Influencing factors: trimmed situational/ demographic, psychological, physiological	0.48					
	Age		-0.28	0.18	-0.12	-1.59	0.114
	Gender		6.68	4.89	0.10	1.37	0.175
	Race		-8.67	5.44	-0.11	-1.60	0.113
	Anxiety		2.81	0.65	0.38	4.31	0.000
	Depression		1.96	0.72	0.22	2.72	0.008
	Comorbid conditions		4.95	1.23	0.27	4.03	0.000

of hemodialysis. Of the physiological influencing factors, CAS was significantly correlated with age, anxiety, depression, and marital status (see Table 6). Chemistry Abnormality Scores were lower in older patients but higher in those reporting more anxiety, depression, and unmarried marital status. Comorbid conditions and marital status were also significantly correlated. Patients who were not married reported higher numbers of comorbid conditions. Dialysis adequacy was significantly correlated only with gender. Average Kt/V values were higher in females, indicating a higher delivered dose of dialysis.

Of the physiologic variables, CAS ($r = 0.23, p < 0.01$) and numbers of comorbid conditions ($r = 0.34, p < 0.01$) were significantly correlated with total symptom scores. Correlations between all individual laboratory values and physical symptoms were also computed. Significant correlations were noted between phosphorus levels and itching ($r = 0.27, p < 0.05$), shortness of breath ($r = 0.32, p < 0.05$), and chest pain ($r = 0.63$, $p < 0.01$). Blood urea nitrogen and sleep ($r = 0.30, p < 0.01$) and serum glutamic-oxaloacetic transaminase and joint pain ($r = 0.26, p < 0.05$) were significantly correlated as well.

At this point in the analysis, physiological influencing factors in combination with trimmed situational/ demographic and psychological variables accounted for 50% of the variance in symptom scores ($R^2 = 0.50$, $F(9,110) = 12.40$, $MSE = 671.79$, $p = 0.00$). Refer to Table 7, regression 3 for the results of this analysis. Anxiety and depression were again significant predictors of symptom scores. Of the physiological factors, only comorbidity was significant. Laboratory values, adequacy of dialysis, and level of education were dropped from the model because they were nonsignificant predictors of symptom scores at $p \geq 0.50$.

The last regression in this series of analyses was conducted including the situational/demographic, psychological, and physiological influencing factors that were retained in the model. The final model accounted for 48% of the variance in symptom scores ($R^2 = 0.48$, $F(6, 122) = 18.53$, $MSE = 687.14$, $p = 0.00$) (see Table 7, regression 4). Significant predictors of symptom scores include: anxiety, depression, and numbers of comorbid conditions. The standardized regression coefficient for anxiety was $\beta = 0.38$, $t(122) = 4.31$, $p < 0.00$, for depression $\beta = 0.22$, $t(122) = 2.72$, $p < 0.01$, and for comorbid conditions $\beta = 0.27$, $t(122) = 4.03$, $p < 0.00$. Thus, a person who was one standard deviation above the mean on anxiety was 0.38 standard deviations above the mean on symptom score. Likewise, a person who was one standard deviation above the mean on depression was 0.22 standard deviations above the mean on symptom score. Finally, a person who was one standard deviation above the mean on number of comorbid conditions was 0.27 standard deviations above the mean on symptom score. Examination of tolerance showed no indication of multicollinearity, although values for anxiety (0.56) and depression (0.63) were somewhat low.

Question 2: What are the characteristics of symptoms reported by ESRD hemodialysis patients in relation to the following symptom dimensions: symptom occurrence (i.e., severity, frequency, duration), symptom distress, and symptom concurrence? Primarily descriptive statistics were used to investigate the multidimensional characteristics of symptoms reported by patients in this study. Factor analysis was employed to explore the dimension of concurrence.

Table 8 presents an overall summary of several symptom characteristics. The average total symptom score was 13.41, rated on a 0-20 scale. The typical symptom was

Table 8

Average Characteristics of Symptoms Reported by Hemodialysis Patients

Characteristic	Range of possible scores	*M*	*SD*
Number of symptoms reported	NA	5.67	2.63
Symptom score	0-20	13.41	2.57
Symptom severity	0-5	3.63	0.68
Symptom frequency	0-5	3.33	0.93
Symptom duration	0-5	2.96	0.96
Symptom distress	0-5	3.50	1.03
Symptom relief score	0-30	14.48	6.73

Note: NA = Not applicable

moderate to severe in severity (3.63), occurred every other day (3.33), lasted approximately half of the day (2.96) and was moderately to severely distressing (3.50). All dimensions were rated on a 0-5 scale. Of the 11 symptoms assessed, muscle weakness received the highest total symptom score. Scores for joint pain, problems sleeping, and tiredness followed in descending order. The lowest score was for nausea/vomiting (see Table 9).

Muscle weakness was also rated as the most frequently occurring symptom ($M = 4.30$, SD 1.30) as well as the longest lasting ($M = 4.30$, $SD = 1.33$) and the most distressing ($M = 4.03$, $SD = 1.23$). Cramps of all types were rated as the most severe symptom ($M = 4.12$, $SD = 1.00$). However, cramps typically lasted less than a quarter of the day ($M = 2.10$, $SD = 1.07$) and happened only 1-2 times per week ($M = 1.66$, $SD = 1.19$). When they did occur, though, cramps were moderately distressing ($M = 3.79$, $SD = 1.37$). Difficulty sleeping, ranked as the second most prevalent and severe symptom ($M = 4.02$, $SD = 1.07$), occurred with regularity ($M = 3.94$, SD = 1.22), was long lasting ($M = 3.71$, SD = 0.85), and was severely distressing ($M = 3.76$, SD = 1.51) to patients. Ratings for severity, frequency, duration, and distress associated with each symptom are presented in Table 9.

An inspection of the dimension ratings (i.e., severity, frequency, duration, and distress) for each symptom failed to reveal any obvious trends in the scores. No one dimension was consistently rated the highest or lowest. Correlations were also calculated between the means of each of the symptom dimension in an attempt to uncover any patterns in their relationships (see Table 10). A high correlation was found between severity and distress ($r = 0.71, p < 0.01$). Symptoms that were severe were highly

Table 9

Average Symptom Scores, Symptom Dimension Ratings, and Level of Relief Scores for Each Symptom

Symptom	Total symptom score* *M (SD)*	Average Severity** *M (SD)*	Average frequency** *M (SD)*	Average Duration** *M (SD)*	Average Distress** *M (SD)*	Total relief Score*** *M (SD)*
Muscle weakness	16.26 (3.88)	3.61 (1.04)	4.30 (1.30)	4.30 (1.33)	4.03 (1.23)	5.55 (8.40)
Joint pain	15.48 (3.48)	3.83 (0.89)	4.13 (1.35)	3.67 (1.50)	3.86 (1.27)	14.21 (9.70)
Problems sleeping	15.42 (3.28)	4.02 (1.07)	3.94 (1.22)	3.71 (0.85)	3.76 (1.51)	11.20 (10.35)
Tiredness	14.65 (3.34)	3.49 (0.88)	4.01 (1.06)	3.76 (1.37)	3.39 (1.37)	12.23 (9.23)
Abdominal pain	13.67 (4.26)	3.94 (1.06)	3.11 (1.78)	3.06 (1.92)	3.56 (1.92)	14.94 (11.52)
Itching	13.45 (3.90)	3.91 (1.15)	3.38 (1.66)	2.46 (1.65)	3.70 (1.32)	17.27 (10.67)
Headaches	12.26 (3.47)	3.62 (1.02)	2.33 (1.08)	2.77 (1.71)	3.54 (1.21)	18.72 (7.76)
Short of breath	12.16 (3.99)	3.28 (1.20)	2.98 (1.58)	2.26 (1.53)	3.65 (1.45)	17.47 (10.23)
Cramps	11.68 (3.10)	4.12 (1.00)	2.10 (1.07)	1.66 (1.19)	3.79 (1.37)	19.60 (9.20)
Chest pain	11.53 (3.79)	3.35 (1.00)	1.88 (1.32)	2.35 (1.73)	3.94 (1.30)	15.38 (10.04)
Nausea / vomiting	11.49 (3.52)	3.59 (1.18)	2.71 (1.31)	1.76 (1.11)	3.44 (1.38)	13.05 (11.90)

Note. Possible range of scores: *0-20. ** 0-5. *** 0-30. In all cases, higher scores indicate higher levels of the variable.

Table 10

Correlations Between Symptom Dimensions

	Mean severity	Mean frequency	Mean duration	Mean distress
Mean severity	--	0.11	0.36**	0.77**
Mean frequency		--	0.55**	0.04
Mean duration			--	0.32**
Mean Distress				--

Note. ** $p \leq 0.01$

distressing as well. Greater severity was also associated with longer duration ($r = 0.36, p < 0.01$). The dimensions related to the timing of symptoms were also significantly correlated ($r = 0.55, p < 0.01$). Those that lasted the longest also occurred with the greatest regularity. The frequency with which a symptom occurred was not significantly associated with either its severity or distress, however.

Exploratory factor analysis was used to investigate the remaining symptom dimension, concurrence. Appropriate use of factor analysis was determined with tests of sampling adequacy and multivariate normality. A value of 0.70 was obtained for the Kaiser-Mayer-Olkin (KMO) Measure of Sampling Adequacy. This value fell above the 'middling' range as well as the 0.5 minimum acceptable for factorability (Brown, 2001; George & Mallery, 2003). Bartlett's Test of Sphericity was 199.60, $p \leq 0.00$, indicating that the data were approximately multivariate normal and did not produce an identity matrix (George & Mallery, 2003).

Principal components factor analysis with varimax rotation was used to extract the factors. Three criteria were used to determine number of factors: the Kaiser-Guttman rule, the scree plot, and theoretical soundness (Nunnally & Bernstein, 1994). Examination of the scree plot suggested the extraction of three factors. However, four components emerged with eigenvalues > 1.0, suggesting a four factor solution according to the Kaiser-Guttmann criterion. After examination of the symptoms that loaded on each factor, it was decided to retain a four factor solution on theoretical grounds. The symptoms that were grouped together had a common thread.

The loadings of the symptoms on the four factors are shown in Table 11. Based on sample sizes of 100 to 200, factor loadings of 0.384 to 0.512 are the suggested minimum

Table 11

Results of Principal Components Factor Analysis with Varimax Rotation Including Factor Loadings

Symptom	Factor 1	2	3	4
Tiredness	0.78			
Sleeping problems	0.69			
Muscle weakness	0.59			
Shortness of breath		0.82		
Chest pain		0.79		
Joint pain			0.80	
Headaches			0.63	
Itching			0.46	
Nausea/vomiting				0.81
Abdominal pain				0.75

(Stevens, 2002). In this sample of 130, factor loadings ranged from 0.46 to 0.82. One symptom, cramps, loaded equally on factor 2 (i.e., shortness of breath and chest pain) and factor 4 (nausea/vomiting and abdominal pain). However, since cramps did not correlate strongly with any of the symptoms on either factor, it was dropped from the analysis. The factor solution presented was derived after the elimination of cramps.

Three items loaded saliently on Factor 1. Tiredness, sleeping problems, and muscle weakness were all related to energy/vitality. Factor 2 included chest pain and shortness of breath, symptoms typically associated with cardiac related problems. A pain/comfort theme was apparent among the symptoms comprising Factor 3 (i.e., joint pain, headache, and itching). Nausea/vomiting and abdominal pain loaded on Factor 4, both of which accompany problems related to the gastrointestinal system.

The four factor solution accounted for 62.49% of the variance in the model. Fit of the factor structure was assessed by generating a reproduced correlation matrix. Small residuals indicated that the model was accurate in its initial explanation of the total variance of the variables in the model (Brown, 2001).

Further analysis of each factor was done to determine changes in individual symptom scores and Quality of Life Index (QLI) scores in the presence of increasing numbers of symptoms in the grouping. As can be seen from Table 12, individual symptom scores increased as numbers of symptoms in the cluster increased. The greatest increase in scores occurred with the addition of a third symptom. QLI scores declined with increasing numbers of symptoms. Figure 6 illustrates the relationship between numbers of symptoms and QLI scores. From the graph it appears that the greatest decrease in QLI scores occurred with the addition of a second symptom.

Table12

Change in Individual Symptom Scores with Increasing Numbers of Symptoms in the Cluster

	Total symptom score		
	1 Symptom	2 Symptoms	3 Symptoms
Factor 1			
Tiredness	13.33	13.93	16.15
Problems sleeping	NA	15.29	16.35
Muscle weakness	NA	NA	17.15
Factor 2			
Shortness of breath	11.03	14.77	NA
Chest pain	NA	12.15	NA
Factor 3			
Joint pain	14.76	15.13	17.00
Itching	NA	13.73	16.00
Headache	NA	NA	14.29
Factor 4			
Nausea/vomiting	11.29	11.92	NA
Abdominal pain	NA	13.69	NA

Note: NA = not applicable

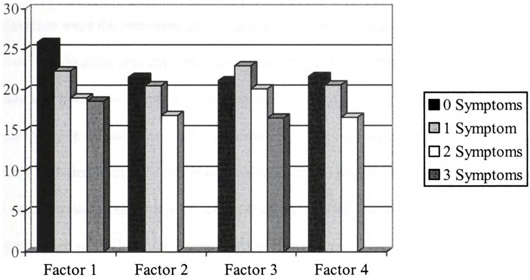

Figure 6. Quality of life scores relative to the number of symptoms in the cluster reported.

Question 3: What strategies are used by ESRD hemodialysis patients to relieve symptoms? Patients used a variety of both self-initiated and prescribed methods in their efforts to obtain symptom relief. As can be seen in Table 13, medication and rest/relaxation were the strategies most commonly employed to relieve an assortment of symptoms. Medication was used most frequently to relieve different types of pain as well as itching and problems sleeping. Often medication was used in combination with other methods for more effective relief. For example, the treatment regimen for headache frequently included both medication and rest/sleep/relaxation. The majority of patients (55%) used rest/sleep/relaxation for relief of tiredness. Twenty-four percent of patients who complained of difficulty sleeping used distraction as a method of coping. However, this strategy was not effective in terms of symptom relief.

Patients used the widest array of strategies to relieve muscle cramps. Rather than medication, they used a variety of alternative techniques including: stretching, walking, and massage. Indicating the removal of too much fluid, cramps that occurred during dialysis sessions were relieved by the administration of saline intravenously. The most original method used by patients was eating pickles. Pickles were thought to replace sodium and water lost with overly aggressive fluid removal during hemodialysis.

For all symptoms assessed, a portion of the patients did nothing to obtain relief. This was especially noteworthy in the case of muscle weakness, the symptom that received the highest symptom score. Of the patients who reported muscle weakness, 24% indicated that they used no specific strategy to increase strength. Eighteen percent of the patients stated that they exercised to build strength, but none did so with any regularity. Refer to Table 13 for a summary of methods used to relieve all symptoms studied.

Table 13

Strategies Used by Patients to Relieve Symptoms

	Symptom *n* (valid %)*					
Relief Strategy	Tiredness	Itching	Headache	Problems sleeping	Joint pain	Cramps
Nothing	18 (18)	5 (9)	2 (5)	14 (17)	11 (18)	5 (7)
Medication	9 (9)	28 (50)	33 (85)	47 (57)	39 (62)	20 (29)
Rest/sleep/ relaxation	72 (72)	0	18 (46)	10 (12)	15 (24)	4 (6)
Exercise	8 (8)	NA	NA	NA	9 (14)	23 (34)
Distraction	13 (13)	0	0	31 (89)	1 (2)	0
Skin care	NA	28 (50)	NA	NA	NA	NA
Cut out daytime nap	NA	NA	NA	3 (4)	NA	NA
Cut out caffeine and alcohol	NA	NA	NA	1 (1)	NA	NA
Change position	NA	NA	NA	NA	NA	NA
Change breathing pattern	NA	NA	NA	NA	NA	NA
Change eating pattern	NA	NA	NA	NA	NA	NA
Other	8 (8)	20 (36)	9 (23)	35 (43)	18 (29)	46 (68)

Note. * *n* (valid %) = number and percent of patients reporting the symptom who used the strategy. NA = not applicable to the symptom.

Table 13 (continued)

	Symptom *n* (valid %)*				
Relief Strategy	Shortness of breath	Chest pain	Nausea vomiting	Abdominal pain	Muscle weakness
Nothing	8 (19)	3 (18)	14 (11)	6 (33)	31 (46)
Medication	6 (14)	10 (59)	18 (44)	8 (44)	5 (8)
Rest/sleep/ relaxation	24 (56)	4 (24)	5 (12)	4 (22)	15 (22)
Exercise	NA	NA	NA	NA	23 (34)
Distraction	1 (2)	0	2 (5)	0	0
Skin care	NA	NA	NA	NA	NA
Cut out daytime nap	NA	NA	NA	NA	NA
Cut out caffeine and alcohol	NA	NA	NA	NA	NA
Change position	8 (19)	2 (12)	NA	3 (17)	NA
Change breathing pattern	4 (9)	NA	NA	NA	NA
Change eating pattern	NA	NA	9 (22)	NA	NA
Other	13 (30)	3 (18)	6 (15)	4 (22)	3 (5)

Note. * *n* (valid %) = number and percent of patients reporting the symptom who use the strategy. NA = not applicable to the symptom.

Question 4: What level of symptom relief is achieved by ESRD hemodialysis patients? Refer back to Table 9 for the total relief scores for all symptoms assessed. Possible scores ranged from 0 to 30. For this sample, relief scores ranged from 5.55 to 19.60 (*M* = 14.48, *SD* = 6.73), with higher scores indicative of greater relief. The symptom with the highest symptom score, muscle weakness was also the least effectively relieved (*M* = 5.55, *SD* = 8.40). The related symptoms of sleeping problems (*M* = 11.20, *SD* = 10.35) and tiredness (*M* = 12.23, *SD* = 9.23) were ranked as the second and third least effectively relieved. Although rated as the most severe, cramps received one of the lowest symptom scores and the highest relief score.

To determine the extent to which patients were satisfied with the level of relief they obtained from symptoms, the scores on the satisfaction subscale of the symptom relief tool were examined. Scores for individual symptoms ranged from 1.17 to 3.84, rated on a 0-5 point scale with higher scores indicative of greater satisfaction. Patients were the least satisfied with relief from muscle weakness, most satisfied with relief from cramps. Mean satisfaction scores for the remaining symptoms included: sleeping problems (2.27), nausea/vomiting (2.49), abdominal pain (2.61), tiredness (2.68), joint pain (2.92), chest pain (3.25), itching (3.29), shortness of breath (3.47), and headache (3.80). Again, higher scores correspond to greater relief.

Question 5: What is the relationship between influencing factors and symptoms and the QOL reported by ESRD hemodialysis patients? Correlation and regression analysis were used to examine the relationship among influencing factors, symptoms, and QOL. The correlations among these variables are presented in Table 14. Special note is made of the correlations between influencing factors and QOL and symptoms and QOL.

Table 14

Correlations Among Trimmed Influencing Factors, Symptoms, Level of Symptom Relief, and Quality of Life

	Age	Gender	Race	Anxiety	Depression	Comorbid conditions	Symptom score	Symptom relief score	Quality of life
Age	--	-0.05	-0.32**	-0.43**	-0.17*	0.03	-0.29**	-0.10	0.39**
Gender		--	0.05	0.15	-0.15	0.08	0.14	0.17	0.05
Race			--	0.05	-0.09	-0.11	-0.10	-0.05	0.10
Anxiety				--	0.53**	0.03	0.57**	0.16	-0.60**
Depression					--	0.17	0.49**	0.21*	-0.73**
Comorbid conditions						--	0.34**	0.21*	-0.22*
Symptom score							--	0.53**	-0.51**
Symptom relief score								--	-0.14
Quality of life									--

Note. * $p \leq 0.05$, ** $p \leq 0.01$

tionship among influencing factors and symptoms has been previously discussed. s significantly and positively related to age. As age increased, QOL improved. depression, comorbid conditions, and symptom scores were all significantly and ly correlated with QOL. Increasing anxiety, depression, numbers of comorbid ns, and symptom scores were accompanied by a decrease in self-reported QOL.

eparate regression analyses were conducted to determine which symptom ns and symptom clusters (factors 1-4 identified earlier) were significant s of QLI scores. QLI scores were regressed on the mean scores for each of the dimensions. Of severity, frequency, duration, and distress, only distress was significantly predict QLI scores (β = -0.36, $t(124) = -3.08$, $p = 0.00$). Greater distress was associated with diminished QOL. Twenty percent of the variance ores was accounted for by the model; distress accounted for 6%. In addition, it l that tolerances ranged from 0.48-0.67, providing evidence of shared variance e dimensions.

LI scores were also regressed on the four factors (clusters) identified with the f symptom concurrence. Prior to performing the regression analysis, a score uted for each factor. The factor score was simply the average of the symptom nprising the factor. Factor 1, including tiredness, sleeping problems, and akness, was the strongest predictor of QLI scores (β = -0.40, $t(125) = -4.85$, The presence of this cluster of symptoms was related to lower QOL.

ltiple regression was again used to examine the impact of influencing factors oms on QOL. The results of this analysis with QOL as the dependent variable ed in Table 15. QOL was first regressed on the situational/demographic,

Table 15

Summary of Regression Equations Identifying Predictors of Quality of Life

Regression	Independent variables	R^2	B	SE	β	*t*	*p*
1	Influencing factors	0.67					
	Age		0.09	0.02	0.27	4.46	0.000
	Gender		0.24	0.55	0.02	0.44	0.663
	Race		1.61	0.62	0.15	2.61	0.010
	Anxiety		-0.22	0.07	-0.21	-2.96	0.004
	Depression		-0.69	0.08	-8.40	-8.40	0.000
	Comorbid conditions		-0.26	0.14	-0.10	-1.90	0.060
2	Influencing factors, symptom scores	0.67					
	Age		0.09	0.02	0.27	4.41	0.000
	Race		1.60	0.62	0.15	2.57	0.011
	Anxiety		-0.21	0.08	-0.19	-2.65	0.009
	Depression		-0.70	0.08	-0.55	-8.65	0.000
	Comorbid conditions		-0.25	0.15	-0.10	-1.69	0.094
	Symptom scores		-0.00	0.01	-0.01	-0.13	0.896
3	Influencing factors, symptom scores, level of relief	0.69					
	Age		0.09	0.02	0.28	4.66	0.000
	Race		1.73	0.62	0.16	2.81	0.006
	Anxiety		-0.17	0.08	-0.16	-2.23	0.028
	Depression		-0.70	0.08	-0.56	-8.86	0.000
	Comorbid conditions		-0.28	0.15	-0.11	-1.91	0.058
	Symptom scores		-0.01	0.01	-0.09	-1.08	0.284
	Level of relief		0.01	0.01	0.10	1.63	0.105

Table 15 (continued)

Regression	Independent variables	R^2	B	SE	β	*t*	*p*
4	Influencing factors, symptom scores, level of relief, interaction	0.68					
	Age		0.10	0.02	0.32	5.35	0.000
	Race		1.65	0.63	0.15	2.64	0.009
	Depression		-0.78	0.08	-0.62	-10.30	0.000
	Comorbid conditions		-0.26	0.15	-0.10	-1.83	0.070
	Symptom scores		-0.02	0.01	-0.16	-2.24	0.027
	Level of relief		0.03	0.01	0.20	2.92	0.004
	Interaction		-0.0004	0.00	-0.12	-2.11	0.037
5	Influencing factors, symptom scores, level of relief	0.66					
	Age		0.10	0.02	0.31	5.13	0.000
	Race		1.45	0.63	0.13	2.31	0.023
	Depression		-0.76	0.08	-0.60	-9.96	0.000
	Comorbid conditions		-0.25	0.15	-0.10	-1.69	0.094
	Symptom scores		-0.03	0.01	-0.17	-2.34	0.021
	Level of relief		0.02	0.01	0.14	2.25	0.027

psychological, and physiological influencing factors that were previously identified as predictors of symptoms. The model that included influencing factors resulted in $R^2 = 0.67$, $F(6,122) = 41.89$, $MSE = 8.82$, $p = 0.00$. Age, race, anxiety, and depression were significant predictors of QOL. Older age and Black race predicted higher levels of QOL. Conversely, higher levels of anxiety and depression predicted lower levels of QOL. Gender was removed from the model at this point because it was nonsignificant at $p \geq 0.50$.

Symptom scores were then added to the regression. See Table 15, regression 2. This model accounted for 67% of the variance in QOL. Symptoms did not predict any unique variance in QOL over and above the influencing factors ($R^2 = 0.67$, $F(6,122) = 41.80$, $MSE = 8.83$, $p = 0.00$). Age, race, anxiety, and depression were again significant predictors of QOL. Symptom scores alone had no impact. However, symptom scores were retained in the model to examine their influence with the addition of level of relief.

Question 6: What is the moderating effect of level of symptom relief on the relationship between symptom scores and QOL? Level of relief was added to the regression model as a first step in exploring its potential moderating effect on the relationship between symptoms and QOL. As with symptom scores, a total relief score was computed for all participants by summing relief scores for all reported symptoms. As can be seen in regression 3 on Table 15, neither symptom scores nor relief scores were significant predictors of QOL. The addition of level of relief increased the amount of variance accounted for in QOL by 2%. However, symptom scores moved closer to significance. Anxiety was removed from the model following this analysis because of low tolerance (0.49). Low tolerance indicated that much of the variance was shared by other variables. As noted in Table 14, anxiety was highly correlated with depression, symptom scores, and QOL.

The interaction between symptom scores and level of relief was then included in the model to determine if level of symptom relief had a moderating influence on the relationship between symptom scores and QOL (see Table 15, regression 4). In this model, age, race, depression, symptom scores, and level of relief were significant predictors of QLI scores. The interaction between symptom scores and level of relief was significant as well. However, the interaction added approximately only 1% of the variance to the model. The meaning of the interaction was also not clear and counterintuitive conceptually. The interaction indicated that low symptom scores were related to low QLI scores when level of relief was high. In an attempt to better understand the interaction, QLI scores were regressed on symptom scores, level of relief, and the interaction. Both symptom scores and level of relief remained significant predictors of QOL but the interaction was nonsignificant ($\beta = 0.00$, $t(125) = 0.01$, $p = 0.995$). Because of this and the percent of variance it accounted for in QLI scores, the interaction was removed from the final model.

In the final model, age, race, depression, symptom scores, and level of relief were significant predictors of QOL, accounting for 66% of the variance in QOL scores. It was found that higher QOL was predicted by older age, non-White race, and lower levels of depression and physical symptoms. The standardized coefficient for age was $\beta = 0.31$, $t(122) = 5.13, p < 0.00$. A person who was one standard deviation above the mean on age was 0.31 standard deviations above the mean on QOL. Race also significantly predicted

QOL, with non-Caucasian patients reporting higher levels. Both depression ($\beta = -0.60$, (122) = -9.96, $p < 0.00$) and symptom scores ($\beta = -0.17$, $t(122) = -2.34$, $p = 0.02$) negatively influenced QOL. Individuals who were one standard deviation above the mean on depression and symptom scores were 0.60 and 0.17 standard deviations below the mean on QOL respectively.

The main effect of level of relief on symptoms was positive, such that higher evels of relief predicted higher QOL. Patients who were one standard deviation above he mean on level of relief were 0.14 standard deviations above the mean on QOL. In ight of the results presented, the original theoretical model underlying this study required revision. See Figure 7 for the revised model.

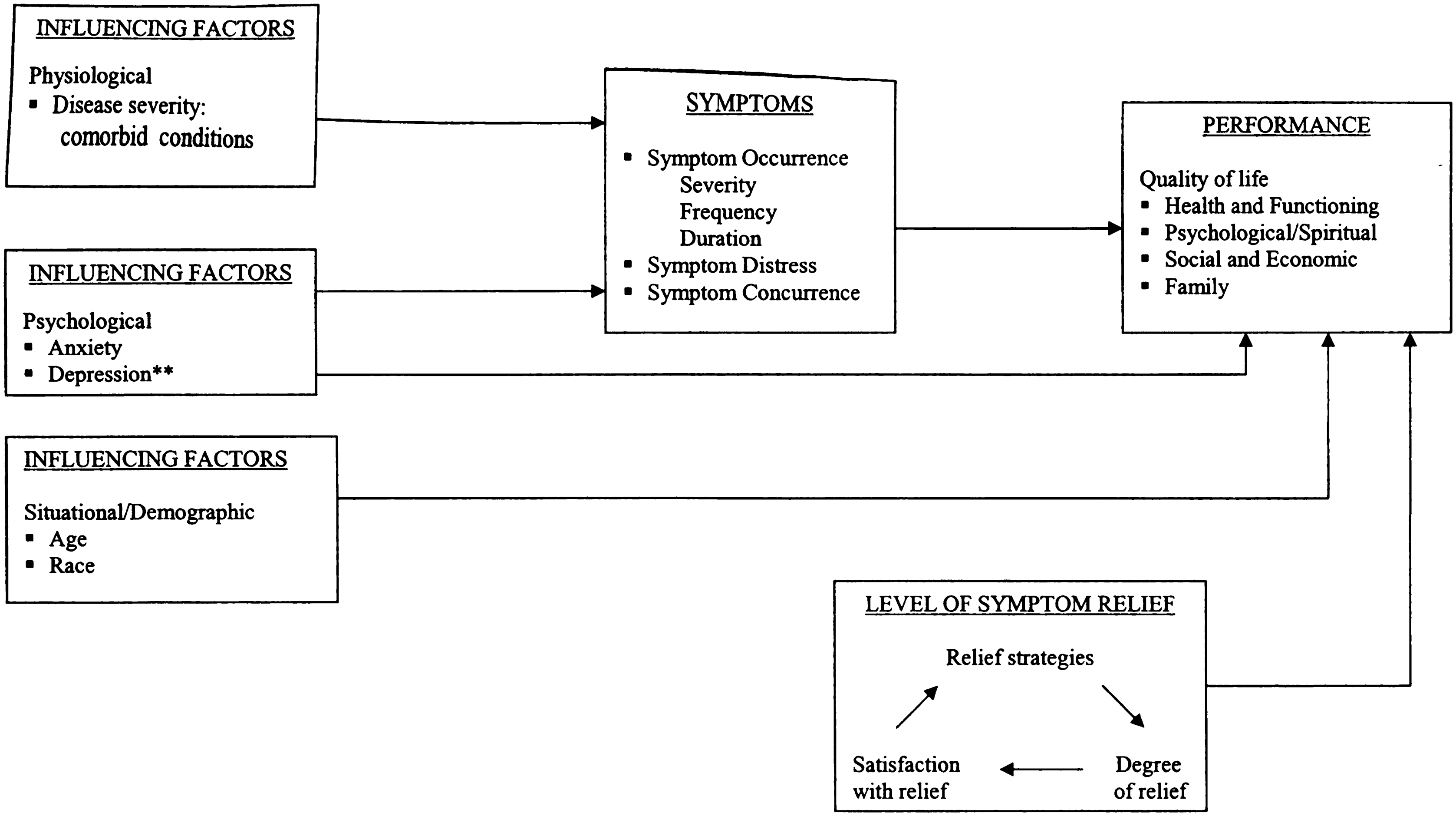

Figure 7. Revised theoretical model

Note: ** significant predictors of both symptoms and QOL.

Chapter 5

DISCUSSION

The potential need for palliative care in the end-stage renal disease (ESRD) population has gone unrecognized by the general healthcare community as well as by those who reimburse for care. End-stage renal disease is a life-limiting illness that places tremendous physical and psychosocial burdens on both patients and families. Despite this fact, hemodialysis patients rarely benefit from services that focus on the unique needs of individuals who anticipate a shortened life span. The inability to access palliative care services occurs for a number of reasons including continued active treatment with hemodialysis, lack of financing, and absence of documentation of the benefits of palliative care to ESRD patients (Moss & ESRD Workgroup, 2001). In addition, there is insufficient empirical evidence to confirm the need for palliative care, especially with respect to symptom relief. Such data are needed to spotlight the issue and capture the attention of healthcare providers, government officials, and private insurers who make crucial decisions regarding reimbursement of services.

This investigation set out to validate the need for palliative care in the ESRD hemodialysis population, specifically in the area of symptom relief. To this end, documentation of the total symptom experience associated with ESRD became the central purpose of the study. Factors that influence symptoms as well as their consequences in terms of QOL were investigated. Extending the examination of symptom experience a step further than in previous research, the degree to which patients obtain relief from their unpleasant symptoms was also assessed.

Influencing factors

The exploration of the symptom experience of hemodialysis patients began with an analysis of a number of factors thought to influence symptoms. Knowledge of the physiological, psychological, and situational/demographic variables that are linked to symptoms enhances the ability of healthcare providers to anticipate, prevent, and relieve them. While some of these factors are amenable to intervention, others are not. However, it is important to consider those factors that cannot be altered because they help to identify patients who are at risk for higher levels of symptoms.

The physiological variables of interest in this investigation were disease severity, defined by degree of metabolic homeostasis and comorbid conditions, and adequacy of dialysis treatments. Low Chemistry Abnormality Scores and Kt/V values within the desired range (i.e., values ≥ 1.2) suggest that hemodialysis was effectively maintaining homeostatic balance for the majority of patients in this sample. Therefore, it was not surprising that these summary indicators of disease severity and dialysis adequacy were not significant predictors of high symptom scores. This finding is noteworthy in that healthcare providers may presume that patients whose laboratory values are within an acceptable range do not experience high levels of symptoms and may result in failure to identify those at risk.

To further investigate the relationship between laboratory values and symptoms, individual blood tests were examined more closely. Only phosphorus and alkaline phosphatase levels exceeded the acceptable range for dialysis patients and neither was significantly related to total symptom score (Good Samaritan Hospital Chronic Dialysis Center, 2003). Phosphorus was related to itching, a symptom commonly thought to accompany elevated levels (Daugirdas & Ing, 1994; Vanholder, Glorieux, De Smet, & De Deyn, 2004). However, Jakic (1999) and Bruni et al. (1989) reported no relation between this laboratory parameter and itching in the hemodialysis patients they studied. It has been suggested that joint pain is associated with increased levels of alkaline phosphatase (Colorado HealthSite, 2004). Although Barrett et al. (1990) validated this relationship, the link between elevated alkaline phosphatase levels and joint pain was not supported in this study. In light of conflicting results of this and previous research, the impact of biochemical abnormalities on the symptoms experienced by hemodialysis patients remains in question.

Of the physiological influencing factors examined, only number of comorbid conditions significantly predicted symptom scores. This is a particularly relevant finding in that ESRD patients experience a high level of morbidity despite technically adequate dialysis treatment (Poppel et al., 2001). According to the United States Renal Data System (2001), 50% of incident patients have three or more comorbid conditions when they begin therapy. As time on dialysis progresses, increasing numbers of concurrent illnesses emerge that compound symptom burden. In this sample of prevalent patients, 85% experienced between 3 and 10 additional comorbidities. Cardiovascular disorders, peripheral vascular disease, diabetes, chronic lung disease, and arthritis were among the conditions that patients experienced, each adding its own constellation of symptoms to the total burden.

The influence of comorbid conditions on symptoms reported by patients in this study is difficult to corroborate with previous research. Barrett et al. (1990) failed to demonstrate a positive relationship between the two factors in a study of hemodialysis patients. On the other hand, Merkus et al. (1999) found that increasing numbers of comorbid illnesses in combination with advanced age lead to higher symptom burden, accounting for 12% of the variance in total symptom score. Although age was not a significant predictor of symptoms in this study, the positive influence of comorbid conditions on symptoms was supported. An additional 7% of the variance in symptom score was explained by the inclusion of comorbid conditions in the model. Although the positive relationship between comorbid conditions and symptoms seems intuitive, conflicting results and limited research make it impossible to conclude with certainty that a connection consistently exists.

Establishing a relationship between psychological influencing factors and symptoms is complicated as well, confounded by the overlap of physical symptoms of illness and psychological distress. However, the link between psychological status and symptoms has been established with greater reliability through the use of measures that eliminate items that are symptomatic of both physical and mental disorders.

The Hospital Anxiety and Depression Scale (HADS) is an example of a tool that relies only on psychic symptoms to assess psychological distress (Zigmond & Snaith, 1983). Because dialysis patients suffer from a number of physical symptoms that are also indicative of psychological disorders, researchers have used this instrument to assess anxiety and depression in this population. In all cases, anxiety and depression were significantly correlated to physical symptom scores (Killingworth & Van Den Akker, 1996; McCann & Boore, 2000).

Using the HADS to measure anxiety and depression, the findings of this study further validate the connection between psychological status and physical symptoms. Significant correlations were found between anxiety and depression and both total symptom scores and nearly all of the individual symptom scores. In addition, anxiety and depression together were the strongest predictors of symptoms, accounting for 24% of the variance in symptom scores. These findings provide evidence of the dynamic nature of the mind-body interaction. The data also lend insight into areas where interventions by healthcare providers may improve the comfort and well-being of patients.

The unanswered question of cause and effect complicates the choice of the most appropriate intervention. The theoretical model for this study depicts a linear relationship between psychological factors and symptoms, with the implication that anxiety and depression lead to higher symptom scores. However, the cross-sectional nature of this study does not allow for determination of a causal relationship between psychological factors and somatic symptoms. This is due, in part, to the inability to determine the temporal ordering of variables with a cross-sectional design.

Furthermore, recent research with other patient populations does not uphold the inference of a causal link from psychological status to physical symptoms. In a recent study, structural equation modeling was used to test the Theory of Unpleasant Symptoms in a sample of newly diagnosed lung cancer patients (Jablonski, Gift, von Eye, Given, & Given, 2004). Rather than depression directly affecting symptoms, the opposing relationship was noted. Higher levels of symptoms resulted in less positive mental health and higher levels of depression. The direction of this relationship was supported in a longitudinal study conducted by Kurtz and colleagues (2002), who found that symptom severity was a significant predictor of depressive symptoms in elderly lung cancer patients. In light of these findings, longitudinal rather than cross-sectional research is needed to clarify the direction of the relationship between psychological status and symptoms in the ESRD hemodialysis population.

Finally, none of the situational/demographic influencing factors (age, gender, race, marital status, level of education, length of time on dialysis) included in this study were significantly related to symptom scores. McCann and Boore (2000) assessed the impact of these same factors on the fatigue experienced by hemodialysis patients with the identical results. Only age was positively related to nausea and headaches in a study conducted by Barrett et al. (1990). Merkus and colleagues (1999) were unable to demonstrate an independent effect of demographic characteristics on level of symptomatology as well.

These results question the need to include this category of influencing factors in the theoretical model underlying this study. However, it may be that situational variables that do affect symptoms have not yet been identified. Lifestyle factors such as diet and exercise, availability and access to healthcare resources, and social support are examples of situational factors that conceivably impact symptoms but were not examined in this investigation (Kimmel et al., 1995). Exploration of the effect of a greater variety of situational/demographic factors is needed prior to removing this category of influencing factors from the model.

Symptoms

Crucial to any effort to validate the need for palliative care services in the ESRD population is an in-depth analysis of the symptoms experienced by patients. To this end, the number, variety, and nature of symptoms reported by patients in this sample were systematically explored. Data indicated the presence of a relatively high number and variety of symptoms. Of the 11 physical symptoms routinely assessed, patients recounted an average of five. Upon further questioning, patients also reported a wide assortment of additional symptoms involving several body systems. Among them were changes in taste, smell, and vision (sensory); anorexia, thirst, and constipation (gastrointestinal); and numbness/burning in hands/feet and restless legs (peripheral vascular and neurological).

As anticipated, the prevalence of symptoms in this sample mirrored that reported in the literature. Tiredness, problems sleeping, cramps, muscle weakness, and numbness in the hands/feet were the top five symptoms experienced by patients in this study. Although rankings varied slightly, the majority of studies also reported these symptoms among the most commonly occurring (Barrett et al., 1990; Curtin, Bultman, & Thomas-Hawkins, 2002; Killingworth & Van Den Akker, 1996; McCann & Boore, 2000; Merkus et al., 1999; Parfrey et al., 1988). Nausea/vomiting, chest pain, abdominal pain, and headaches, while less prevalent, were still reported by a fair number of patients in this and previous studies (Merkus et al., 1999; Parfrey et al., 1988). The presence of an array of additional symptoms such as those noted in this study has been documented in the literature as well, providing further evidence that multiple symptoms are a common occurrence in the lives of hemodialysis patients (Curtin, Bultman, & Thomas-Hawkins, 2002).

A thorough investigation of the symptoms experienced by hemodialysis patients, however, requires more than knowledge of their prevalence. In this study, analysis of symptoms extended beyond prevalence to an examination of their characteristics as well. Previous research has typically focused on limited aspects of symptoms, primarily their occurrence and severity or frequency (Curtin et al., 2002; Killingworth & Van Den Akker, 1996; Parfrey et al., 1987). In this study, a multidimensional profile was constructed for each of the 11 physical symptoms including its severity, frequency of occurrence, duration, and associated distress. A total score was also calculated for each symptom by summing the ratings given on each of these four dimensions.

An advantage of this summary score was that it provided a means by which to estimate how problematic each symptom was both individually and relative to other symptoms. Individual symptom scores revealed that patients in this sample experienced high levels of symptoms. All symptoms were rated above the midpoint of the possible range of scores, 0 to 20. Muscle weakness received the highest score at 16.26. Not surprising, tiredness and problems sleeping also received high scores. Nausea/vomiting received the lowest score at 11.49. Having access to summary symptom scores is beneficial in that it allows healthcare providers to estimate the relative importance of each symptom to the patient and prioritize interventions to relieve them.

A disadvantage of the summary scores, however, was that they obscured the unique contribution of each of the symptom dimensions. For example, in this study nausea/vomiting and chest pain received similar mean symptom scores, 11.49 and 11.53 respectively. However, ratings given the individual dimensions were dissimilar. Although chest pain occurred infrequently and was of moderate severity, it lasted as much as half the day and was perceived as severely bothersome. Nausea/vomiting, on the other hand, occurred more often and with greater severity, but it did not last as long and was only moderately bothersome. Summary symptom scores permitted a judgment as to how problematic these symptoms were in general terms but the relative influence of each dimension could not be established.

Severity, frequency, duration, and distress ratings were examined for each of the symptoms in an effort to determine the differential impact of each dimension on the experience of the symptoms. However, it was not possible to distinguish any pattern among the individual dimension ratings. No one dimension was consistently rated higher or lower than the others and three of the four dimensions were significantly intercorrelated. These findings suggest that the experience of a symptom is shaped by the interplay of all of its dimensions, making it difficult to disentangle the influence of one dimension from the other. This conclusion draws attention to the need for multidimensional symptom assessment.

Symptom assessment is typically limited to severity, a practice that is reinforced in the clinical setting. A prime example is the widespread measurement of pain using a 10-point severity scale. This routine not only ignores the patient's reactions to how often pain occurs and how long it lasts, but also discounts the emotional response to the symptom. Assessment of both the cognitive (i.e., perception of severity, frequency and duration) and emotional (i.e., perception of distress) response to symptoms is fundamental to symptom management efforts. Multidimensional assessment contributes data that aids the design of interventions that treat the symptom from multiple angles, hopefully resulting in greater relief. Despite the potential advantages, measurement of all symptom dimensions is not yet standard clinical practice.

To further explore the benefits of multidimensional symptom assessment, symptom dimensions were also examined in relation to QOL, the outcome of interest in this study and a major focus of palliative care. Only the degree of distress associated with symptoms was found to be a significant predictor of QOL, accounting for 6% of the variance in Quality of Life Index scores. This relationship between symptom distress and QOL was recognized by McDaniel and Rhodes (1995) in an earlier analysis of symptom experience. In their middle-range TOUS, Lenz and colleagues (1997) also suggested that it is symptom distress that most contributes to QOL. The results of this study lend strength to these theoretical claims.

The finding that symptom distress predicts QOL also reinforces the importance of this dimension as a focus of assessment and intervention. In addition, McDaniel and Rhodes (1995) emphasized the importance of assessing symptom distress to identify the patient's affective response to symptoms, to motivate self-management of symptoms, and to evaluate the effectiveness of different modes of treatment. However, especially in hemodialysis clinics where one nurse is responsible for several patients, the technical aspects of care critical to maintain patients' lives often overwhelm concern for the QOL they experience. Frequently the time needed to thoroughly assess all symptom dimensions as well as plan and implement appropriate interventions is not available. Although not evaluated in this study, it is also conceivable that the staff do not possess the expert knowledge necessary to provide this care. This reality adds leverage to the plea for access to and reimbursement for palliative care services in this population.

Finally, the analysis of symptoms reported by patients in this study was completed with an examination of the dimension of concurrence. Interest in this dimension has gained momentum in recent years, as evidenced by increasing numbers of conference presentations and papers published on the topic (Dodd et al., 2001b; Gift, Stommel, Jablonski, & Given, 2003; Miller, Nail, Rosenfeld, & Perrin, 2004). Research investigating symptom concurrence (i.e., clusters), however, is still in its infancy despite this emergent attention. Furthermore, this study represents the first attempt to explore this dimension in the ESRD population.

According to Dodd et al. (2001b), a symptom cluster is defined as three or more concurrent symptoms that are related to each other. In addition, convention indicates that a factor (i.e., cluster) should be composed of a minimum of three variables (Factor analysis, 1995). In this study, four groupings emerged from the 11 physical symptoms assessed including: 1) energy/vitality, 2) cardiac functioning, 3) pain/comfort, and 4) gastrointestional functioning. Not all of these groups of symptoms qualified as clusters as defined by the criteria noted previously. It appeared that the limited number of symptoms included in the analysis was responsible for two factors being defined by only two symptoms. However, since the symptoms in each factor were theoretically related and demonstrated acceptable factor loadings, they were considered clusters in this study.

It has been hypothesized that concurrent symptoms not only interact to alter the perception of each individual symptom but also impact outcomes in a synergistic manner (Dodd et al., 2001b; Lenz et al., 1997). The clusters identified in this study supported this hypothesis to a degree. Individual symptom scores increased as numbers of symptoms in the cluster increased. In contrast, QOL decreased in the presence of each additional symptom in the cluster. All of the clusters followed this pattern.

This relationship has been documented in previous studies, but with cancer patients. In a study of newly diagnosed elderly lung cancer patients, Gift and colleagues (2004) reported a strong positive correlation between number of symptoms in the cluster and severity of symptoms. An association between increasing numbers of symptoms and patient outcomes was also noted. Patients who reported higher numbers of symptoms in a given cluster also experienced decreased physical functioning. Similar findings have also been reported by Dodd et al. (2001b), noting diminished functional status in the presence of the cluster including pain, sleep insufficiency, and fatigue.

Also of interest was the link between each of the clusters and QOL. In this analysis, rather than examining the impact of individual symptoms on the cluster, the influence of the cluster as a unit was assessed. The energy/vitality cluster, including tiredness, sleeping problems, and muscle weakness, was the strongest predictor of QOL. Given the number of patients reporting these symptoms as highly problematic, this finding has significant clinical ramifications. It is suggested that interventions targeted toward this cluster of symptoms may yield a dramatic improvement in the QOL of hemodialysis patients. However, research is needed to test this hypothesis.

Based on the results of this study, it appears as though hemodialysis patients suffer from a substantial number and wide variety of unpleasant symptoms. In addition, symptoms that co-occur further increase symptom burden and diminish QOL. The distress associated with the symptoms adversely influences QOL as well. In light of these findings, a key end result of this exploration of symptoms is a beginning validation of the need for palliative care in the hemodialysis population.

Level of Symptom Relief

Knowledge of the prevalence and characteristics of symptoms that accompany ESRD is insufficient to build a definitive case for palliative care. The extent to which symptoms are relieved is of paramount importance to the argument as well. A deficiency in existing theoretical models of symptom experience and symptom management is that this concept is not included as a key component. Neither the TOUS (Lenz et al., 1997) nor the Symptom Management Model developed by Dodd and colleagues (2001a) explicitly incorporates level of relief as an outcome. As a consequence, the current research literature lacks documentation of the level of relief patients obtain from their symptoms. Since this information is necessary to validate or refute the need for palliative care, level of relief was a focus of this investigation.

Hemodialysis patients in this study experienced only fair relief from their symptoms. This conclusion is supported by a mean relief score of 14.48, which is well below the maximum possible of 30. Further analysis of individual symptoms suggested that the vaguest symptoms in terms of etiology and treatment were also the least well relieved. Muscle weakness, problems sleeping, and tiredness are examples of symptoms that have multiple causes but few effective remedies. These symptoms ranked the highest in terms of symptom scores and the lowest with respect to relief. Interestingly, they also formed the cluster of symptoms that had the greatest impact on QOL. These findings point to an urgent need to target this group of symptoms for intervention and research.

Upon examination of the satisfaction component of the relief scores, it became apparent that patients were not entirely satisfied with the amount of relief they obtained from their symptoms. However, anecdotal comments made by patients during the interviews raised doubt as to validity of the satisfaction scores they reported. Their remarks suggested that resignation or acceptance better described their response to level of symptom relief than satisfaction. When questioned regarding satisfaction with relief, one common response was “I guess I’m satisfied, what else can I do about it.” This comment implied that patients were resigned to live with symptoms they believed to be untreatable. An equally frequent comment, "You just take it as it is because it's all a part of the illness," alluded to acceptance of symptoms that were thought to be unavoidable consequences of ESRD and its treatment. In light of these statements, patients' satisfaction scores may, in fact, reflect level of resignation or acceptance rather than satisfaction.

This interpretation suggests one explanation for why some of the patients in this study did nothing to manage their symptoms. For example, 24% of the patients who complained of muscle weakness employed no particular tactic to improve their strength. If the previous assumption is correct, the question arises as to what factors lead to feelings of passive resignation and unquestioning acceptance of symptoms. While some of the patients in this study used a variety of strategies to relieve symptoms, others did not. The physiological, psychological, and situational/demographic factors that contribute to this discrepancy in behavior among patients were beyond the scope of this study and are yet to be determined.

Documentation of the need for palliative care in the hemodialysis population was further advanced by this examination of the level of symptom relief reported by the patients in this study. To this point in the discussion, it has been determined that patients experienced a variety of symptoms, several of which were not effectively relieved. Furthermore, patients were not completely satisfied with the level of relief they obtained from their symptoms. The argument for palliative care is not complete without examination of the impact of symptoms on QOL.

Quality of Life

The ultimate outcome of interest to palliative care is the QOL of patients who live in the shadow of a life-limiting illness. Symptoms are a major focus of concern since they have been shown to have a significant negative effect on QOL. Previous research has documented the impact of symptoms on the QOL of patients with ESRD. Without exception, these studies have demonstrated that distressing symptoms detract from dialysis patients' well-being and enjoyment of life (Curtin et al., 2002; Killingworth & Van Den Akker, 1996; Merkus et al., 1999; Parfrey et al., 1988). It was not surprising, then, when the results of this study reinforced this relationship between symptoms and QOL. Patients with high symptom scores reported lower QOL than those with low symptom scores.

The QOL of patients in this study was also influenced by how well their symptoms were relieved, a relationship that has not been previously reported in the literature. Symptom relief scores were significant predictors of QOL scores such that low levels of symptom relief were predictive of diminished QOL. This finding causes one to view symptom experience from a slightly different perspective than in the past. The primary focus of attention becomes level of relief, the direct anticipated outcome of intervention, and its indirect beneficiary, QOL. This does not detract from the importance of the relationship between symptoms and QOL, but spotlights the actions required to bring about relief.

Limitations

While this study contributes to an improved understanding of the symptom experience and QOL of hemodialysis patients, findings must be considered in light of its limitations. A number of design and methodological issues are acknowledged for this reason.

The cross-sectional design of this investigation prevents the confirmation of causal links between variables. A significant correlation between variables suggests only that they are related and the direction of the relationship. It cannot be stated with any certainty, for example, that high symptom scores caused diminished QOL even though they were negatively related. Only longitudinal studies can demonstrate the temporal ordering of variables necessary for validation of cause and effect.

Cautious interpretation of study results is also suggested due to the timing of data collection. All participant interviews were conducted on treatment days during dialysis sessions. Although consistent with previous research with hemodialysis patients, this design may introduce a bias toward reporting symptoms that occur at one point in time. Fluctuations in symptoms that may occur on off-dialysis days may not be captured as a consequence. This hypothesis was supported in one study in which patients stated that they feel so different during dialysis treatments that they doubt that responses made then accurately reflect the interdialytic period (Meyer et al., 1994, p. 271). In this study, patients were asked to report symptoms in relation to the past month to moderate the impact of this variation in status. However, recall for past events has been shown to be inaccurate and biased (Stone, Shiffman, Schwartz, Broderick, & Hufford, 2002). There may also be a tendency for patients to focus on symptoms that are present at the moment because they overshadow experiences of the recent past.

An additional limitation of this study related to the timing of data collection is the use of laboratory values to compute Chemistry Abnormality Scores (CAS) that did not coincide exactly with assessment of symptoms. Because blood is drawn routinely only one time per month, very few of the patient interviews were conducted on the same day.

It is conceivable that blood chemistry values fluctuate from day to day. This variation in metabolic status was validated to an extent in this study. There was essentially no correlation found between the previous month's and the current month's CAS values ($r = -0.01, p = 0.95$). As a consequence, the CAS computed from the most current laboratory tests may not accurately reflect physiological status at the time of the interview. This could potentially result in an inaccurate assessment of the impact of abnormal blood values on symptoms. However, it was not feasible to interview all patients on blood draw days.

The instruments used to measure symptoms and level of symptom relief must also be mentioned as a study limitation. Both of the tools were developed specifically for this study because the research questions could not be satisfactorily answered with existing measures. However, both instruments performed well and produced the expected results. Patients had no difficulty understanding or responding to individual items. Neither measure took an inordinate amount of time to complete. However, it is suggested that items evaluating relief relative to each symptom dimension could be removed without loss of clinically relevant information. The overall relief item and the satisfaction item resulted in sufficient data to determine level of symptom relief. Test-retest reliability for each of the tools was adequate. Scores obtained for both symptoms and level of relief at Time 1 were not significantly different from those at Time 2. A moderate correlation between the two relief scores, however, suggests the need to further refine that instrument.

Implications for Nursing Practice and Research

Despite its limitations, this study has implications for both clinical practice and research relative to each component of symptom experience model that guides this study. While some findings have immediate clinical applicability, others raise more questions that require further research.

Influencing factors. Of all of the physiological, psychological, and situational/demographic influencing factors examined in this study, anxiety and depression were most strongly correlated to symptoms and QOL. Both disorders were linked to increased levels of symptoms. The presence of depression also predicted diminished QOL. Despite their negative impact on patients' lives, routine screening for anxiety and depression in hemodialysis patients is not typical of current clinical practice. The reasons for this lack of attention to the psychological status of patients were not the focus of this investigation. However, it is suggested that in the practice setting, inadequate staffing levels force nurses to focus on the technical aspects of care to the neglect of less urgent matters. Undocumented observations made in two busy dialysis clinics during data collection suggest this to be the case. Nurses were justifiably preoccupied supervising the technical aspects of dialysis for 6-12 patients, leaving little time to handle less pressing issues. The initiation of a palliative care program in the dialysis setting with staff who have time to attend to the psychological needs of patients is proposed as one solution to this situation. There is an urgent need to take action to improve patient outcomes.

While the findings of this study regarding anxiety and depression have direct clinical application, research is needed to further clarify the impact of both physiological and situational influencing factors on symptoms and QOL. Research to identify additional physiological correlates of symptoms is recommended since only comorbidity was shown to be significantly related in this study. For example, the influence interdialytic weight gain, carnitine deficiency, and medication regimens are examples of variables not studied in this investigation that potentially alter symptoms and QOL. Situational factors are an especially fertile area for research since many are amenable to nursing intervention. As mentioned earlier, the influence of variables such as social support, activity patterns, dietary intake, and type of artificial kidney used for dialysis need to be explored. Of the situational variables examined in this study, none provided direction for intervention to improve patient status. Both categories of influencing factors require further exploration.

Symptoms. Some of the insights that emerged from this study relative to symptoms can be confidently used in clinical practice. Other findings raise further questions to be answered before application to patient care is warranted. The need for multidimensional symptom assessment has been described. However, time constraints in the clinical setting as well as the lack of quick, easy assessment tools limit the feasibility of multidimensional evaluation at this time. Nonetheless, the addition of distress to symptom assessment is recommended. The distress dimension was the only one that was found to be a significant predictor of QOL. Including patients' evaluations of the distress associated with symptoms is straightforward and has the potential to provide valuable information to guide interventions and enhance QOL.

Already alluded to, the availability of multidimensional assessment tools would enhance nurses' ability to completely evaluate patients' symptoms. Research is needed to develop these tools for use in both the clinical setting and in research endeavors. Since multidimensional symptom assessment is new to most nurses, exploration of the most effective methods for educating them as to its importance as well as its incorporation into clinical practice is also essential.

Concurrence (i.e., symptom cluster) is a new area of research so it is not surprising that it is a novel concept to practicing nurses as well. Beginning evidence provided by this and a small number of previous studies suggests that it has relevance for clinical practice. At this point, direct clinical application is limited. However, two practical conclusions emerge from this investigation. First, nurses need to be aware that the presence of co-existing symptoms may lead to a more intense symptom experience that negatively impacts QOL. Secondly, one cluster of symptoms that emerged during data analysis requires immediate attention in practice. Muscle weakness, tiredness, and problems sleeping formed a cluster that was clearly troublesome to patients and was negatively related to their QOL. The severity, frequency, duration, and distress associated with these symptoms were ranked among the highest of the 11 physical symptoms assessed.

Additional empirical exploration of the concept of concurrence is warranted to further delineate its significance for clinical practice. This includes examination of the consistency with which symptom clusters occur in multiple samples of hemodialysis patients, the interaction of symptoms in the cluster, and the impact of symptom clusters on patient outcomes. Refinement and standardization of the statistical methods used to analyze symptom concurrence is also needed to enhance comparison of findings across studies and patient populations.

Level of symptom relief. The symptom cluster comprised of muscle weakness, tiredness, and problems sleeping was not only identified as the most troublesome in this study but the least effectively relieved as well. It was also the cluster that was the strongest predictor of diminished QOL. Therefore, it is imperative that nurses who have frequent contact with hemodialysis patients focus on the management of these pervasive symptoms. Doing so may significantly enhance the QOL of afflicted patients.

However, all three of the symptoms in this cluster are complex in terms of both their etiology and treatment. Effective therapies are elusive. Clinical intervention studies are needed to determine treatment modalities that will alleviate or, at a minimum, diminish the impact of these symptoms. Although patients failed to obtain adequate relief from other symptoms as well, muscle weakness, tiredness, and problems sleeping seemed to be the most distressing to patients in this study.

Nurses are educated to provide holistic care. In the real world of everyday clinical practice, however, insufficient time often limits their ability to do so. High nurse-patient ratios and high illness acuity frequently result in greater emphasis on accomplishing tasks than on meeting less immediate patient needs. The results of this study challenge nurses to redirect their time and effort to two areas of particular importance to QOL, psychological status and symptom management. Greater attention to the emotional and physical comfort of patients may enhance their QOL. This investigation has also shown that more research is needed to supply nurses with the knowledge and tools they need to accomplish this task.

Conclusion

ESRD patients live in a limbo, suspended between life and death. Without the life-sustaining technology of dialysis, they face certain death. Even with dialysis, their continued survival is jeopardized by potential complications such as loss of dialysis access and the worsening of comorbid conditions. ESRD patients' daily lives are stressed by the expectation of a significantly shortened life span and the constant threat of death.

Dialysis patients' lives are also overshadowed by the stress of living each day with a grave, incurable illness. End-stage renal disease places significant adaptive demands on both patients and families. The treatment regimen, including dialysis, dietary changes, and fluid restriction, requires permanent lifestyle changes that affect all aspects of life. Daily life is difficult for both patients and families as a result.

Hemodialysis patients are especially appropriate recipients of palliative care because of these challenges. Advanced care planning as well as other ethical, psychosocial, and spiritual issues that arise due to limited life span have to be addressed. Patients must also cope with threats to the quality of their daily living such as symptoms and treatment side effects. Palliative care specializes in helping patients and families manage these matters.

However, ESRD patients are not typically beneficiaries of these specialized services. The need for palliative care in this population of patients has not been well documented. A primary objective of this study was to provide the empirical evidence necessary to justify access to palliative care, especially with respect to symptom management. Several pertinent findings help to accomplish this goal, the most significant being reports of unrelieved symptoms that negatively influence QOL. At a minimum, these results focus attention on ESRD patients who are unable to access specialized services that have helped to improve the lives of patients with other chronic illness such as cancer, congestive heart failure, and chronic lung disease. This study is offered as a plea to healthcare providers, government officials, and private insurers, with the power to remedy this injustice, to support efforts to improve the lives of this vulnerable and forgotten group of patients through palliative care.

APPENDICES

Demographic Information

Subject Identification #_________________ Date______________

Day of week (circle one):	M	T	W	Th	F	S
	1	2	3	4	5	6

Shift (check one):
7:00 AM _____ (1) 12:00 PM _____ (2) 5:00 PM _____ (3)

1. Age ____________ years

2. What is the highest level of school you have completed?

	(circle one number)
8th grade or less	1
Some high school	2
High school diploma or GED	3
Vocational school or some college	4
College degree	5
Professional or graduate degree	6

3. What is your gender?

	(circle one number)
Male	1
Female	2

4. How do you describe yourself

	(circle one number)
African American or Black	1
Hispanic or Latino	2
Native American or American Indian	3
Asian or Pacific Islander	4
White, non Hispanic	5
Other (please specify)_________________	6

5. What is your marital status?

	(circle one number)
Married, living with husband/wife	1
Single, never married	2
Divorced/separated	3
Widowed	4

6. Do you have children?

(circle one number)

No................. 0
Yes................ 1 → If yes, how many children do you have? ______________

How many children live with you? ________

7. What is your current employment status?

(circle one number)

Employed full time.................................... 1
Employed part time.................................. 2
Retired... 3
Disabled... 4
Not employed for reasons unrelated to health..... 5

8. How long have you been on hemodialysis? ___________ months/years (circle one)

9. Do you need help with personal care?

(circle one number)

No............. 0
Yes........... 1 → If yes, who helps?

spouse........... 1
child.............. 2
friend............ 3
paid assistant.... 4
other.............. 5

How many days/week does he/she help? _________

How many hours/day does he/she help? __________

10. Do you need help with household chores?

(circle one number)

No............. 0
Yes........... 1 → If yes, who helps?

spouse.......... 1
child............ 2
friend........... 3
paid assistant... 4
other........... 5

How many days/week does he/she help? __________

How many hours/day does he/she help? __________

11. Do you have any of the following health problems?

	(circle all that apply) No	 Yes
heart attack	0	1
heart failure (fluid in lungs/heart doesn't pump well)	0	1
clogged arteries in your legs	0	1
numbness in feet/legs	0	1
stroke	0	1
chronic lung disease (emphysema, bronchitis)	0	1
stomach ulcer/reflux disease	0	1
diabetes	0	1
arthritis	0	1
lupus	0	1
fibromyalgia	0	1
cirrhosis of the liver	0	1
cancer	0	1

12. Please list any other health problems that you have.

____
____
____
____
____

Chemistry Abnormality Score

Study Identification #________________
Check one: Current month___________ Previous month___________

Laboratory Value	Actual Value	Criterion Values	Points
K (mEq/L)		5.9 or <	0
		6.0 or >	1
BUN (mg/dL)		100 or <	0
		101 or >	1
Creatinine-female (mg/dL)		14.9 or <	0
		15.0 or >	1
Creatinine-male (mg/dL)		19.9 or <	0
		20.0 or >	1
Hct (%)		26 or >	0
		20-25	1
		19 or <	2
SGPT (U/L)		49 or <	0
		50-200	1
		201 or >	2
SGOT (U/L)		49 or <	0
		50-200	1
		201 or >	2
Alk Phos (U/L)		99 or <	0
		100-200	1
		201 or >	2
Total Protein (G/dL)		6.0 or >	0
		4.0-5.9	1
		3.9 or <	2
Albumin (G/dL)		3.0 or >	0
		2.0-2.9	1
		1.9 or <	2
Triglycerides (mg/dL)		< 2x normal limits	0
		2x-3x normal limits	1
		3x or more > normal limits	2
CO_2 (mEq/L)		20.1 or >	0
		15-20	1
		14.9 or <	2
Ca^{++} (mg/dL)		9.0-11.0	0
		7.0-8.99 or 11.01-13.0	1
		6.99 or < or 13.01 or >	2
$PO_4^{=}$ (mg/dL)		2.5-6	0
		6.1-8.0	1
		8.0 or > or 2.49 or <	2

Symptoms and Level of Symptom Relief

Study Identification # ____________________ Date: __________

Day of week completed: M T W Th F S

I am interested in learning about the symptoms you have. I have a list of 11 symptoms that are commonly experienced by kidney patients. I will ask you if you have experienced each of the symptoms in the past month. If so, I will ask you some further questions about the symptom. I will also ask some questions about how you relieve the symptom and the amount of relief you get.

Symptom #1: Tiredness

1. Have you experienced **tiredness** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom #2

A. How severe is the tiredness? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you feel tired? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the tiredness last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the tiredness? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

1. If you experience **tiredness,** please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)______________________
_____ Rest/sleep/relaxation
_____ Exercise
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the tiredness.

B. When you use the methods checked above to relieve the tiredness, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the tiredness? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the tiredness? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you feel tired? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the tiredness lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the tiredness? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #2: Itching

2. Have you experienced **itching** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom #3

A. How severe is the itching? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you itch? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the itching last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the itching? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

2. If you experience **itching**, please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)_______________________
_____ Rest/sleep/relaxation
_____ Do skin care (for example, put on lotion, take a bath)
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the itching.

B. When you use the methods checked above to relieve the itching, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the itching? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the itching? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you itch? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the itching lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the itching? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #3: Headaches

3. Have you experienced **headaches** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom #4

A. How severe are the headaches? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you have a headache? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the headache last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the headaches? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

3. If you experience **headaches**, please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)_______________________
_____ Rest/sleep/relaxation
_____ Massage
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the headaches.

B. When you use the methods checked above to relieve the headaches, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the headaches? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the headaches? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you have headaches? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the headaches lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the headaches? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #4: Problems Sleeping

4. Have you experienced **problems sleeping** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom #5

A. How severe are the problems sleeping? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you have problems sleeping? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other night	most nights	every night

C. On average, how long does it take you to fall asleep?

1	2	3	4	5
not long	few minutes	an hour	awake most of the night	awake all night

D. How bothered are you by the problems sleeping? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

4. If you experience **problems sleeping**, please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)______________________
_____ Rest/relaxation
_____ Cut out daytime naps
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving your problems sleeping.

B. When you use the methods checked above to relieve your problems sleeping, how much relief do you get? (circle one)

No relief	0	1	2	3	4	5	Total relief

C. How satisfied are you with the amount of relief you get from your problems sleeping? (circle one)

Not at all satisfied	0	1	2	3	4	5	Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of your problems sleeping? (circle one)

Not at all	0	1	2	3	4	5	Very much

2) decrease **how often** you have problems sleeping? (circle one)

Not at all	0	1	2	3	4	5	Very much

3) decrease **how long** it takes you to get to sleep? (circle one)

Not at all	0	1	2	3	4	5	Very much

4) make you **less upset** by your sleeping problems? (circle one)

Not at all	0	1	2	3	4	5	Very much

Problem #5: Joint Pain

5. Have you experienced **joint pain** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom #6

A. How severe is the joint pain? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you have joint pain? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the joint pain last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the joint pain? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

5. If you experience **joint pain**, please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)________________________
_____ Rest/limit activity/relaxation
_____ Exercise
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the joint pain.

B. When you use the methods checked above to relieve the joint pain, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the joint pain? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the joint pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you have joint pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the joint pain lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the joint pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #6: Cramps

6. Have you experienced **cramps** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom #7

A. How severe are the cramps? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you have cramps? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long do the cramps last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the cramps? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

6. If you experience **cramps,** please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)______________________
_____ Rest/limit activity/relaxation
_____ Exercise
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the cramps.

B. When you use the methods checked above to relieve the cramps, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the cramps? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the cramps? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you have cramps? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the cramps lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the cramps? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #7: Shortness of Breath

7. Have you experienced **shortness of breath** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom 8

A. How severe is the shortness of breath? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you feel short of breath? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the shortness of breath last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the shortness of breath? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

7. If you experience **shortness of breath,** please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)____________________________
_____ Rest/sleep/relaxation
_____ Change the way you are breathing (for example; purse your lips, deep breathe)
_____ Distract yourself (for example; read, watch TV, listen to music)
_____ Other (for example; use fan, open window)____________________
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the shortness of breath.

B. When you use the methods checked above to relieve the shortness of breath, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the shortness of breath? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the shortness of breath? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you have shortness of breath? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the shortness of breath lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the shortness of breath? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #8: Chest Pain

8. Have you experienced **chest pain** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom #9

A. How severe is the chest pain? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you have chest pain? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the chest pain last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the chest pain? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

8. If you experience **chest pain**, please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)______________________
_____ Rest/sleep/relaxation
_____ Change position
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the chest pain.

B. When you use the methods checked above to relieve the chest pain, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the chest pain? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the chest pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you have chest pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the chest pain lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the chest pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #9: Nausea and/or Vomiting

9. Have you experienced **nausea/vomiting** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom #10

A. How severe is the nausea/vomiting? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you have nausea/vomiting? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the nausea/vomiting last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the nausea/vomiting? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

9. If you experience **nausea/vomiting,** please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)_______________________
_____ Rest/sleep/relaxation
_____ Change eating pattern (for example; eat small meals often)
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the nausea/vomiting.

B. When you use the methods checked above to relieve the nausea/vomiting, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the nausea/vomiting? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the nausea/vomiting? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you have nausea/vomiting? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the nausea/vomiting lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the nausea/vomiting? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #10: Abdominal Pain

10. Have you experienced **abdominal pain** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to symptom 11

A. How severe is the abdominal pain? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you have abdominal pain? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the abdominal pain last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the abdominal pain? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

10. If you experience **abdominal pain**, please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)_______________________
_____ Rest/sleep/relaxation
_____ Change position
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the abdominal pain.

B. When you use the methods checked above to relieve the abdominal pain, how much relief do you get? (circle one)

No relief 0 1 2 3 4 5 Total relief

C. How satisfied are you with the amount of relief you get from the abdominal pain? (circle one)

Not at all satisfied 0 1 2 3 4 5 Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the abdominal pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

2) decrease **how often** you have abdominal pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

3) decrease **how long** the abdominal pain lasts? (circle one)

Not at all 0 1 2 3 4 5 Very much

4) make you **less upset** by the abdominal pain? (circle one)

Not at all 0 1 2 3 4 5 Very much

Symptom #11: Muscle Weakness

11. Have you experienced **muscle weakness** in the past month?

☐ Yes **If yes, answer questions below and on the next page.**
☐ No If no, go to the last page.

A. How severe is the muscle weakness? (circle one)

1	2	3	4	5
not at all	mild	moderate	severe	very severe

B. On average, how often do you have muscle weakness? (circle one)

1	2	3	4	5
not often	1-2 times a week	every other day	most days	every day

C. On average, how long does the muscle weakness last? (circle one)

1	2	3	4	5
not long	quarter of the day	half of the day	most of the day	all day

D. How bothered are you by the muscle weakness? (circle one)

1	2	3	4	5
a little bothered	mildly bothered	moderately bothered	severely bothered	very severely bothered

11. If you experience **muscle weakness**, please place an **X** on the line next to ALL of the methods you use to try to relieve it and answer questions A – D

_____ Nothing
_____ Take medicine. Name of medicine(s)______________________
_____ Rest/sleep/relaxation
_____ Exercise
_____ Distract yourself (for example, read, watch TV, listen to music)
_____ Other ____
____

A. Of the methods checked above, please **circle** the one that you think is the **most** effective in relieving the muscle weakness.

B. When you use the methods checked above to relieve the muscle weakness, how much relief do you get? (circle one)

No relief	0	1	2	3	4	5	Total relief

C. How satisfied are you with the amount of relief you get from the muscle weakness? (circle one)

Not at all satisfied	0	1	2	3	4	5	Completely satisfied

D. **How much** do the methods checked above:

1) decrease the **severity** of the muscle weakness? (circle one)

Not at all	0	1	2	3	4	5	Very much

2) decrease **how often** you have muscle weakness? (circle one)

Not at all	0	1	2	3	4	5	Very much

3) decrease **how long** the muscle weakness lasts? (circle one)

Not at all	0	1	2	3	4	5	Very much

4) make you **less upset** by the muscle weakness? (circle one)

Not at all	0	1	2	3	4	5	Very much

12. Are there any other symptoms that you experienced in the past month? If so, list them below along with what you did to get relief and how effective it was.

Symptom	Method of Relief	Effectiveness 0 (not at all effective) 5 (completely effective)

Study Identification #________________ Date _____________

Day of week (circle one): M T W TH F S

Besides learning about your physical symptoms, I am also interested in learning how you feel emotionally. I will read you a question and four responses. Tell me which response best fits how you have been feeling in the past week.

1. I feel tense or 'wound up':
   A. most of the time
   B. a lot of the time
   C. from time to time, occasionally
   D. not at all

2. I still enjoy the things I used to enjoy:
   A. definitely as much
   B. not quite so much
   C. only a little
   D. hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
   A. very definitely and quite badly
   B. yes, but not too badly
   C. a little, but it doesn't worry me
   D. not at all

4. I can laugh and see the funny side of things:
   A. as much as I always could
   B. not quite so much now
   C. definitely not so much now
   D. not at all

5. Worrying thoughts go through my mind:
   A. a great deal of the time
   B. a lot of the time
   C. from time to time but not too often
   D. only occasionally

6. I feel cheerful:
    A. not at all
    B. not often
    C. sometimes
    D. most of the time

7. I can sit at ease and feel relaxed:
    A. definitely
    B. usually
    C. not often
    D. not at all

8. I feel as if I am slowed down:
    A. nearly all of the time
    B. very often
    C. sometimes
    D. not at all

9. I get assort of frightened feeling like ‘butterflies’ in the stomach:
    A. not at all
    B. occasionally
    C. quite often
    D. very often

10. I have lost interest in my appearance:
    A. definitely
    B. I don’t take so much care as I should
    C. I may not take quite as much care
    D. I take just as much care as ever

11. I feel restless as if I have to be on the move:
    A. very much indeed
    B. quite a lot
    C. not very much
    D. not at all

12. I look forward with enjoyment to things:
    A. as much as I ever did
    B. rather less than I used to
    C. definitely less than I used to
    D. hardly at all

13. I get sudden feelings of panic:
    A. very often indeed
    B. quite often
    C. not very often
    D. not at all

14. I can enjoy a good book or radio or TV program:
    A. often
    B. sometimes
    C. not often
    D. very seldom

Ferrans and Powers
QUALITY OF LIFE INDEX©
DIALYSIS VERSION – III

PART 1. For each of the following, please choose the answer that best describes how ***satisfied*** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

1	Very dissatisfied
2	Moderately dissatisfied
3	Slightly dissatisfied
4	Slightly satisfied
5	Moderately satisfied
6	Very satisfied

HOW *SATISFIED* ARE YOU WITH:						
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of energy you have for everyday activities?	1	2	3	4	5	6
4. Your ability to take care of yourself without help?	1	2	3	4	5	6
5. The likelihood you will get a kidney transplant?	1	2	3	4	5	6
6. The changes you have had to make in your life because of kidney failure (such as diet and the need for dialysis)?	1	2	3	4	5	6
7. The amount of control you have over your life?	1	2	3	4	5	6
8. Your chances of living as long as you would like?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6

13. Your spouse, lover, or partner?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. Your friends?	1	2	3	4	5	6
16. The emotional support you get from people other than your family?	1	2	3	4	5	6
17. Your ability to take care of family responsibilities?	1	2	3	4	5	6
18. How useful you are to other people?	1	2	3	4	5	6
19. The amount of worries in your life?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. Your home, apartment, or place where you live?	1	2	3	4	5	6
22. Your job (if employed)?	1	2	3	4	5	6
23. Not having a job (if unemployed, retire, or disables)?	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. How well you can take care of your financial needs?	1	2	3	4	5	6
26. The things you do for fun?	1	2	3	4	5	6
27. Your chances for a happy future?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your faith in God?	1	2	3	4	5	6
30. Your achievement of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6

32. Your life in general?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6

PART 2. For each of the following, please choose the answer that best describes how ***important*** that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW *IMPORTANT* TO YOU IS:						
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of energy you have for everyday activities?	1	2	3	4	5	6
4. Your ability to take care of yourself without help?	1	2	3	4	5	6
5. The likelihood you will get a kidney transplant?	1	2	3	4	5	6
6. The changes you have had to make in your life because of kidney failure (such as diet and the need for dialysis)?	1	2	3	4	5	6
7. The amount of control you have over your life?	1	2	3	4	5	6
8. Your chances of living as long as you would like?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your spouse, lover, or partner?	1	2	3	4	5	6

14. The emotional support you get from your family?	1	2	3	4	5	6
15. Your friends?	1	2	3	4	5	6
16. The emotional support you get from people other than your family?	1	2	3	4	5	6
17. Your ability to take care of family responsibilities?	1	2	3	4	5	6
18. How useful you are to other people?	1	2	3	4	5	6
19. The amount of worries in your life?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. Your home, apartment, or place where you live?	1	2	3	4	5	6
22. Your job (if employed)?	1	2	3	4	5	6
23. Not having a job (if unemployed, retire, or disables)?	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. How well you can take care of your financial needs?	1	2	3	4	5	6
26. The things you do for fun?	1	2	3	4	5	6
27. Your chances for a happy future?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your faith in God?	1	2	3	4	5	6
30. Your achievement of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Your life in general?	1	2	3	4	5	6

33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6

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