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The Perceived Quality of Life in Persons Performing Peritoneal Dialysis

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THE PERCEIVED QUALITY OF LIFE IN
PERSONS PERFORMING PERITONEAL DIALYSIS

By

Paula A. Armstrong

A THESIS

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ABSTRACT

THE PERCEIVED QUALITY OF LIFE
IN PATIENTS PERFORMING PERITONEAL DIALYSIS

By

Paula A. Armstrong

This purpose of this study was to describe the quality of life in patients who independently performed peritoneal dialysis at home for the treatment of end stage renal disease.

A descriptive design was conducted using the Ferrans and Powers Quality of Life Index-dialysis version. A convenience sample of 31 patients from a Midwest dialysis facility participated in the study. Subjects were asked to rate their level of satisfaction and the level of importance of 35 aspects of life. The reported quality of life was reported to be satisfactory. There was a moderate positive correlation between the time on dialysis and reported quality of life. The subjects were satisfied with most areas of their lives. They did not rate the need to get off dialysis or receiving a kidney transplant as important.
This research project is dedicated to all dialysis patients, those I have known and those I have not. It has been a privilege to meet and care for them and their families.

I thank them for teaching me about life.
Acknowledgements

I would like to personally extend my sincere appreciation to those individuals who contributed to my successful completion of this research project.

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CHAPTER ONE

INTRODUCTION

Quality of life (QOL) has been identified as a significant concern in the end stage renal disease (ESRD) population (Evans et al., 1985). ESRD is a chronic, irreversible condition of kidney failure. Treatment modalities for this condition, including renal transplant and dialysis, may prolong life but are not curative. Many patients on chronic dialysis also have co-morbid conditions such as diabetes, cardiovascular disease, and hypertension. At a time when allocation of limited resources is being discussed, the cost of maintenance dialysis treatments is a concern. Since 1972, Medicare has funded a majority of the costs for the treatment of ESRD. Medicare costs for treatment of patients with ESRD have exceeded two billion dollars per year (Jones, 1992). Where treatment options exist, final selection should be based on considerations of cost-effectiveness as well as non-physiologic outcomes such as perceived quality of life.

There is concern that dialysis treatment is being administered to persons with a limited possibility of survival and poor quality of life (Levinsky & Rettig, 1991). Quality of life is an important concern in health care and in the allocation of limited resources (Ferrans & Powers, 1993). Quality of life has been defined in a variety of ways by numerous authors. Ferrans and Powers (1993) point out that the definition of QOL depends on cultural, ethnic, and religious values. In addition, the perception of QOL may be different.
depending on who is assessing it. Bihl, Ferrans, and Powers (1988) and Meers et al. (1995) report that patients may rate their quality of life higher than an observer would. During meetings at the National Conference on Peritoneal Dialysis in February 1995, several recognized experts in the field of peritoneal dialysis (PD) stated that QOL was higher in PD patients than with other forms of renal replacement therapy. This was attributed to the treatment itself and the freedom from machines, clinic, etc. Devins (1990) stated, however, that in the study of QOL between different modes of dialysis systematic differences have not emerged.

It is important for nurses to have knowledge about the patient’s perception of QOL while receiving maintenance dialysis. Nurses often assist patients and their significant others when they are required to make decisions about which treatment option to pursue in the event of chronic renal failure. Nurses frequently consult with the patient and family either pre-dialysis, during the initial treatment, or after treatment has been initiated in an emergent situation to present options for renal replacement therapy. An option that is included in discussion with patients and significant others is the right to decline treatment. If nurses understand the QOL issues that can be anticipated, they may be better able to counsel those who are faced with this decision. Nurses also need to be aware of QOL issues that are important to the patient who is on chronic dialysis.

In this study, the Neuman systems model was used as a guide to the research. The Neuman systems model for nursing provides a comprehensive, flexible, wholistic, and systems-based perspective for nursing practice (Neuman, 1985). This conceptual model focuses attention on the response of the client system to stressors in the environment.
Neuman described the importance of nursing interventions to assist the patient in effectively dealing with stressors in order to maintain stability and optimal wellness. Therefore, the Neuman systems model was the basis for conducting this research to study the perception of QOL of patients with ESRD who are performing PD.

**Purpose**

The purpose of this study was to describe the perceived quality of life (PQOL) of patients performing peritoneal dialysis as a treatment for ESRD. The Ferrans and Powers Quality of Life Index- dialysis version was used to obtain patient perception. This study built on the 1993 study by Ferrans and Powers. In their study, the QOL of patients receiving hemodialysis treatment was examined. Patients performing PD were not included. Therefore this study will add to the body of knowledge with regard to another treatment modality of ESRD.
CHAPTER TWO

REVIEW OF LITERATURE AND CONCEPTUAL FRAMEWORK

A critical review of the literature and the conceptual framework that were used as the basis for this study will be presented in this chapter. The categories of study include: (a) quality of life (QOL) as a concept, (b) QOL in the patient with end stage renal disease (ESRD), (c) the conceptual framework for the study, and (d) conceptual and operational definitions.

Quality of Life - the concept

Burkhardt, Woods, Schultz, and Ziebarth (1989) performed an extensive review of QOL research prior to their study. The results suggested that many research efforts equated objective disease states with QOL. Morbidity, work status, and physiological functional status were misinterpreted as the patients' perception of their QOL. If we are to attempt to understand perceived quality of life, an instrument that uses the person's subjective perceptions and one that includes the domains of life that are important to the person could provide valuable information. The study was conducted using a longitudinal design with data collections three weeks apart. Open-ended questions and four instruments, the QOLS, Duke-UNC Health Profile, Life Satisfaction Index, and either the Arthritis Impact Measurement Scale or the Ostomy Adjustment Scale were administered. The target population was middle-aged to older adults with one of four chronic conditions: diabetes mellitus, ostomy secondary to colon cancer or colitis, osteoarthritis,
or rheumatoid arthritis. The qualitative data indicated that the items of importance to QOL were very similar between persons with or without chronic illness. The differences in scores between the ostomy group and the diabetes group lead the researchers to believe that QOL can vary between a relatively healthy group with a stable chronic condition and a group with active multisystem disease. The findings supported the use of subjective perceptions in the definition of QOL. These subjective perceptions included the domains that were important to the individual and provided valuable information. One limitation of the study was that the time between testing was six weeks. During that period there was little difference in scores. This could be attributed to one of two factors. First, the instruments were not sensitive to change or, second, there was little change in the participants that would affect their QOL. It was suggested that the longer timeframe, months to years, could provide information regarding perceived QOL over time and as the patient's condition changes. Another limitation of the study was the lack of an item that addressed independence. Although independence was implied in several items, such as, participation in recreation and work activities, it was not addressed explicitly.

Gill and Feinstein (1994) reviewed how QOL was examined and measured in the literature. They asserted that most QOL measurements are aimed at the wrong target. Of 570 references from a QOL bibliography, more than half did not mention the term "quality of life." The authors reviewed 75 articles with QOL in the title. In order for an article to be eligible for review quality of life was described or one or more QOL instruments were used. None of the articles distinguished "overall" QOL from health-related QOL. Many articles actually measured health status rather than QOL. QOL is unique from other
measures in health care in that it incorporates the individuals' values and preferences. One recommendation from this article was that participants would be invited to rate not only the severity and magnitude of problems, but also the importance of the problems.

Meeburg (1993) stated that QOL is a phrase that was first introduced in America after the Second World War. She pointed out that QOL as a concept is very complex with as many definitions as persons using the term. The question then is "How can nurses work with clients to improve their QOL if the goal is unclear" (1993, p. 32)? She defined QOL as a feeling of overall life satisfaction determined by the mentally alert individual whose life is being evaluated. Her definition included both subjective and objective components. Meeburg includes external observers in the objective component of QOL. The observers who were outside of the person's living situation can observe a situation differently than the person who is living in the situation. Including an objective perspective allows observers to disagree with the client's perception of their QOL. An example was the person living in poverty that person may rate their QOL as satisfactory, an observer may rate their QOL as less than satisfactory.

Cella (1992) cited a problem with the historical lack of dialogue regarding QOL between specialists who provide palliative care and QOL experts. Today, in some contexts, concern for the quality of our patients' lives has become as important as an all-encompassing regard for the quantity of life. The Federal Food and Drug Administration (FDA) has recently included improvement in QOL as one of two criteria examined in the approval of new anti-cancer medications. Cella asserted that the two fundamental components of the QOL concept are subjectivity and multi-dimensionality.
that QOL can be understood only from the patient's perspective. He also stated that there are various factors that influence this. Underlying processes which include expectations, perceptions of illness, treatment and possible harm can influence patients' perceptions. Individual patients with the same level of impairment may perceive their QOL differently. This is based on their unique ability to adapt to stressors such as their illness and treatment.

Ganz, Lee and Siaw (1991) discussed patient reported QOL as a predictor of survival. In a study of 40 subjects, with metastatic lung cancer, the Functional Living Index (FLIC), a cancer-specific measure was administered. Baseline measures were obtained and the index was repeated every four weeks. The average age of the subjects was sixty-two years. Within the study sample most subjects had a nonsquamous histology, with a Karnofsky performance status (KPS) greater than 80 and less than 5% weight loss. The study compared baseline measurement of QOL to length of survival. Baseline scores ranged from 50 - 152 were approximately normally distributed with a mean value of 107, and a median score of 106.5. Based on initial ratings, the subjects were divided into two groups: a high FLIC group (n = 20) and a low FLIC group (n = 20). The high FLIC group consisted of those whose scores were greater than the median score. The low FLIC group had scores less than the median score. The results showed that the high FLIC group survived a median of 24 weeks, whereas the low FLIC group survived a median of 11.9 weeks. No significant relationship was found between the physical variables and survival time. Although this study had a small sample size, it suggests that evaluation of QOL may contribute information with regard to the patient's prognosis.
Varricchio (1990) observed that patients are often seeking information about the impact of therapies on their daily lives as well as the risks and benefits of treatment options. Her assessment of QOL included three aspects: physical, psychological, and social well being. She stated that the "possible and actual quality of life of a patient should influence the selection of a therapeutic plan" (p. 255). She also addressed the difference in perception of QOL between individuals and their caregivers. The caregivers had different standards for rating a patient’s QOL based on their own expectations of what was possible and optimal for that patient. Perceptions of QOL may be biased as a result of cultural and developmental differences between patients and caregivers. This demonstrates the difficulty when including an observer component rather than subjective ratings in the assessment of perceived QOL.

In 1993 Skeel discussed the dimensions of QOL of most importance to patients with cancer and the disparity between patient and observer’s perceptions. Traditionally, physicians have focused on somatic and physiological complaints and the physical status of the patient. Emotional and psychological issues may not have been addressed.

Jachuck, Brierly, and Jachuck’s study (as cited in Skeel, 1993) illustrate a difference in perception of QOL between physicians, patients and their close companions. The patients were receiving antihypertensive therapy. Ratings were compared after treatment with antihypertensive agents. One hundred percent of physicians in the study reported that their patients had an improved QOL after the beginning of therapy. In contrast, 48% of the patients reported an improvement. Additionally, 44% felt they had no change in their QOL. A decrease in QOL was reported by 8%. Most of the relatives of the patients
indicated that the QOL deteriorated, with 30% reporting that the patient had severe impairment after receiving the therapy. The patient’s relatives related difficulties including impairment in memory, irritability and moodiness, lack of interest and energy, and decline in sexual interest. These issues may not be brought up during routine patient visits.

In a 1985 study by Pearlman and Jonsen, a case description of a man with an acute exacerbation of his chronic lung disease was presented to 205 physicians. The patient was an elderly-looking 65-year-old man who resided in a nursing home. Additional information was available, however, not all physicians sought more details. Assessment of the case based on the physician’s own expectations, experiences and definitions of QOL yielded variations in evaluation. In making a decision to intubate or withhold intubation, QOL was a factor less than one half of the time. Physicians who responded that QOL was a consideration in their decision said that it was a significant factor. There was a significant difference between attending physicians and resident physicians in training. Residents considered QOL more often than attending physicians. Opinions regarding the level of care to provide were divergent to the extent that they came to opposing conclusions with regard to treating or withholding intubation. Thus, decisions made would determine if the patient’s life would end or be prolonged. This suggested that clinical decisions were affected by caregivers, outside observers, evaluating an individual’s QOL without seeking input from the patient. The authors note one obvious problem is a lack of definition for QOL. A limitation of the study was that there was a disparity in the amount of information about the patient. This was dependent on whether the individual physician sought or did not seek additional information that was available. This, however, is reflective of
individual approaches to situations in a clinical setting.

In 1990, Ferrans reviewed definitions of QOL from the literature in order to clarify the term QOL. The article discussed definitions of five aspects of QOL: (1) normal life, (2) happiness/satisfaction, (3) achievement of personal goals, (4) social utility, and (5) natural capacity. One conclusion was that subjective indicators are the most direct measurement of QOL with objective measurements being secondary. Ferrans suggests using the individual as their own standard for what is normal. She asserted that QOL could only be judged by the individual. Her dimensions of QOL included health and functioning, psychological/spiritual, social and economic, and family. Next, the issue was raised whether these dimensions count equally or are certain aspects more important than others. Because each individual has different values, various aspects of life may have different impact on QOL. Ferrans measured the level of importance of each area as well as the level of satisfaction. By including the level of importance, the ratings reflect which aspects of life have the greatest influence on the individuals perceived quality of life.

Quality of Life in End Stage Renal Disease

In 1985, Evans et al. published a multi-center study of 895 patients undergoing dialysis or renal transplantation. Of the 859 patients included in the study, 287 were being treated with home hemodialysis, 347 with in-center hemodialysis, 81 with peritoneal dialysis, and 144 with transplantation. Data included objective as well as subjective measures. Four major categories were studied: sociodemographic, medical, objective indicators of QOL, and subjective indicators of QOL. Sociodemographic variables included age, sex, race and education. Medical variables included primary diagnosis,
comorbidity, length of time on current treatment, and whether there was a history of failed transplant. The purpose of this study was to determine if QOL varied between different treatment modalities. The conclusion was that patients with renal transplantation enjoyed the highest QOL. Other patients with ESRD have a lower objective QOL, for example, work status and functional ability. Patients were compared to the general population using the life satisfaction measures from Campbell, Converse and Rodgers. The results showed that the mean scores for life satisfaction were 5.55 +/- 1.25 versus 5.25 +/- 1.62 in the general population and dialysis patients, respectively. The study demonstrated that, subjectively, QOL may not be as low as previously thought. The authors made the point that although the subjects were not functioning, objectively, as well as people who are well, they were enjoying life. The authors raise the question of which aspects of QOL should be given the greatest weight when it involves making the decision of allocation of resources. In the past, it has been the tendency to weight objective indicators such as ability to work and functional status greater than subjective indicators. In a time when allocation of resources is being considered, it is understandable how objective benefits of treatment might be valued. Evans et al. note that this emphasis reflects a concern about the value of the patient to society. In a discussion of the study, the authors note as a limitation of the study that too few centers were included to allow the results to be generalizable. Characteristics of treatment centers vary and some centers are better at rehabilitating patients than others. Additionally, other case-mix variables could have been included in the analysis and may have altered the adjusted QOL scores.

Bremer, McCauley, Wrona and Johnson (1989) studied QOL in 489 patients with
FSRD Of those, 79 were on CAPD with an average length of treatment of 22.7 months. Participants were required to be on their treatment for a minimum of 90 days. Objective QOL indicators included typical indicators, for example, measures of income, education, activity and employment. Other objective measures were hospitalizations, sleep, sexual performance, and fatigue. The patients reported lower satisfaction with their health than the general population. The subjects on CAPD also rated lower than the general population on general affect, well being, and overall life satisfaction. They also reported feeling more tied down. ESRD patients reported more satisfaction with their religion. They did not differ from the general population on any other subjective QOL measure.

In 1993 Ferrans and Powers studied the QOL in hemodialysis patients. The sample consisted of 349 subjects receiving in-center hemodialysis in the state of Illinois. The mean number of years on dialysis was 4.02 (SD = 3.49) with a range of 0 to 16.67 years. The Ferrans and Powers Quality of Life Index- dialysis version (QOL-dv) was used to measure perceived QOL. The instrument included items in the four domains of health and functioning, social and economic, psychological/spiritual, and family. The subjects were asked to rate their level of satisfaction with each area as well as the level of importance of that item. With regard to QOL, overall, relatively high mean scores were found for the entire QLI and the four subscales. In fact, the QOL scores in this population were only slightly lower than those of a group of 88 healthy persons were. Subjects were most satisfied with the things they valued in the family domain. They also rated these areas to be important. Subjects were the least satisfied in the area of health and functioning. Their own health was rated the highest in importance. Other health and functioning issues were
rated as less important. Financial aspects of life were found to negatively impact of perceived QOL. Financial independence was considered very important, but satisfaction scores were low. With regard to social aspects of life, the areas that involved relationships had the strongest correlation between satisfaction and importance. Subjects were moderately satisfied with these areas and reported them as being moderately or very important. Overall satisfaction with care was found to be moderately correlated with QOL in hemodialysis patients. Subjects reported being moderately satisfied with their health care and dialysis treatments. These areas were considered very important. The authors suggested that having this information may help those involved with dialysis care build on the areas that are positive and try to assist them in areas that are perceived as negatively impacting perceived QOL.

Conceptual Framework

Betty Neuman's Systems Model will be reviewed as the basis on which this study was built. The concepts of QOL and PD will then be discussed in relation to Neuman's model. Betty Neuman's Systems Model (1995) presents the person, or client, as a whole person, a dynamic composite of interrelationships among physiological, psychological, socio-cultural, developmental, and spiritual variables. The person is described as being in constant change or motion and in continuous interaction with their environment. The person, as a system constantly monitors self and makes adjustments as needed, provided that support factors are in place. This ability to adjust is necessary in order to retain, attain, and maintain stability for an optimal health state. In 1972, Neuman and Young described the nursing client as a person who is either dealing with, or anticipating, stress.
The interrelationship of physiological, psychological, socio-cultural, developmental and
spiritual variables can be affected to the degree in which a person is protected against
reactions to stressors. Stressors are defined as tension producing stimuli that have the
potential for causing instability and can alter the dynamic equilibrium of the person.
Neuman describes the person, or client system, in terms of a core structure surrounded by
a series of concentric circles. The core structure includes basic survival factors including
universal, as well as, unique characteristics. These include the innate and genetic factors
as well as the natural strengths and weaknesses of the system. The core also includes such
unique aspects of the person as cognitive ability. The person's response patterns are
determined and regulated by their core structure.

Next, the person, or client system, has circles surrounding the core structure. These
are the lines of resistance and the lines of defense. There are two lines of defense, the
normal and the flexible. Beginning at the outside perimeter, is the flexible line of defense.
It acts as a buffer to protect the normal line of defense from the effect of stressors. If the
stressors are able to get past the flexible line of defense and are able to penetrate the
normal line of defense the core structure will still be protected from the effect of stressors
by the lines of resistance. Lines of resistance are involuntarily activated to protect the
integrity of the core of the client system. An example of this response is the increase in
the number of white blood cells during infection. When a stressor penetrates all of the
defenses in the system and threatens the core structure the result is instability of the client
system, or illness (Meleis, 1991).

Neuman views stressors as intrapersonal, interpersonal and extrapersonal forces.
Intrapersonal stressors are those forces operating within the individual. Examples of intrapersonal stressors that may occur in the person with end stage renal disease on PD are uremia, infection, anemia, neuropathy, and osteodystrophy. Interpersonal stressors are forces that exist between the individual and others. Interpersonal stressors may include alterations in relationships with spouses/significant others or role changes in the family system as well as relationships with members of the person's health care team.

Extrapersonal stressors are forces that exist outside the individual. Extrapersonal stressors may include the dialysis schedule, the space and equipment which are necessary to perform dialysis treatments, problems with transportation for regular and unscheduled visits to the clinic and financial concerns.

In ESRD the disease is so severe that there is a threat to the survival of the core. Without treatment the result would be instability of the core structure to the degree that death would be the result. Dialysis attempts to restore and protect the core. Dialysis may provide stabilization and some semblance of equilibrium but is not able to completely remove all threats to the core. Additionally, the treatment creates new stressors and threats to the lines of defense. The goal of treatment is to restore enough balance in the system to the point that the survival of the core is not threatened. This will be accomplished by increasing resistance to ongoing stressors. Finally, a new equilibrium is created. How a person views the new equilibrium determines how, or to what degree, the person perceives stressors. If the person's perception is that stressors are a threat, they will not be able to achieve balance. On the other hand, if the person does not perceive stress as significant they will be able to achieve balance and stability. These stressors,
according to Neuman's model are capable of reducing the person's line of defense, or resistance, therefore creating instability of the system.

Neuman (1995) states that nursing is concerned with the "reduction of potential or actual stressor reactions" (p221). The goal of nursing is optimal stability or wellness. In this study, optimal stability or wellness is equated with the person's perceived quality of life.

Neuman describes nursing interventions as primary, secondary, and tertiary prevention. Primary prevention is described as the action required to retain system stability. Risk factors associated with stressors are identified and actions are taken to protect the normal lines of defense and strengthen the flexible lines of defense. This intervention is selected when the risk of a stressor is known but has not yet occurred. Secondary prevention is the action, or intervention, that is required to achieve stability. Secondary prevention is related to symptomology, interventions and treatments to strengthen the internal lines of defense. This is selected when a reaction to a stressor has occurred. Tertiary prevention is the action required to maintain the stability of the system after a reaction to a stressor has occurred and then has been stabilized. The goal of tertiary prevention is to prevent additional reactions to stressors and focus on a return to wellness. Neuman (1995) recognized that there may be perceptual distortions between the client and the nurse. Identification of issues related to QOL of persons on PD will provide information about what aspects of life are perceived as important to the individuals as well as the degree of satisfaction with those aspects. This information may be useful in preventing reaction to stressors or assisting the person to regain or maintain stability during a time when the
person is exposed to a number of stressors. This study will use Neuman's systems model as a framework to describe the perceived QOL of patients with ESRD who are independently performing PD.

**Theoretical Definition of Terms**

Perceived quality of life (PQOL) 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 and Powers, 1993).
CHAPTER THREE

METHODS

This study described the perceived quality of life (QOL) in persons with end stage renal disease (ESRD) performing peritoneal dialysis (PD). The study used a descriptive design. Ferrans and Power's Quality of Life Index Dialysis Version (QLI-dv) (Appendix A) was used. The variables of gender, age, race, marital status, number of months on dialysis, number of months on PD, types of PD, presence or absence of diabetes, and stated number of peritonitis episodes were studied to determine differences on the perceived QOL.

Population and Sample

This study was conducted in a freestanding, for profit, outpatient home dialysis unit in southwest Michigan. A convenience sample of 31 persons was tested. Subjects were over the age of 18, able to read, write and understand English. Subjects completed training in PD and were independently performing their PD longer than one month. Subjects in nursing homes or dependent on others for basic needs were excluded from the study, as these people were not independently performing their own dialysis treatment.

Instrument

The instrument used was Ferrans' and Powers' QOL-dv (Ferrans & Powers, 1993). Permission was obtained from the author to use the tool in this study (Appendix B). This tool contained 66 items and was divided into two parts. Part I measured satisfaction with
various aspects of life. These aspects included the domains of health and functioning, socioeconomic, psychological/spiritual and family. Part II asked the subjects to rate the level of importance for each of these items. A six-point scale and definitions for the ratings to measure the range of responses were included. For Part I the response options ranged from “very satisfied” (6) to “very dissatisfied” (1). Part II the range was from “very important” (6) to “very unimportant” (1). Satisfaction responses were paired with the importance responses. Results were then recoded and multiplied to produce an adjusted scale. This method allowed scores to reflect the degree of satisfaction or dissatisfaction with the aspects of their lives that matter most to the subjects. Adjusted item scores were summed to produce domain sub-scale scores and overall QOL scores. Sixty-four items were generic and applicable to all persons. Two additional items were specific to persons receiving dialysis.

Concurrent validity was evaluated by comparing the QLI to the life satisfaction measurement by Campbell, Converse and Rogers (1976). Validity of the QLI was supported by the correlation between scores from the QLI and an overall satisfaction with life question. Instrument correlation for graduate students \( (r = .75) \) and for dialysis patients \( (r .65) \) demonstrated a high degree of overlap.

Test-retest reliability supported the stability of the instrument. Test-retest correlations of .81 and .87 were obtained for dialysis patients and graduate students, respectively. Internal consistency was supported by Cronbach's alphas of .90 for dialysis patients and .93 for graduate students.
Data Collection Procedures

Participants were selected from the outpatient home dialysis department at a freestanding for-profit dialysis unit in southwest Michigan. Patients who met the inclusion criteria were approached for participation. An introductory phone call was made to potential subjects to assure them that there was no obligation to participate and that anonymity would be preserved. Packets were mailed or given to the participants who expressed an interest in participating. A cover letter (Appendix C) accompanied the survey requesting their participation. A self-addressed, stamped envelope was included for the return of the survey. Additionally, a drop box was placed in the dialysis area for subjects to deposit their surveys if they so wished. Reminder postcards were sent three – seven days after the initial mailing. A second reminder and questionnaire were mailed three weeks after the initial mailing. No stipend was offered. Data was collected and analyzed by the researcher.

Subject Rights and Risks

The potential participants may have been known to the researcher. To decrease the risk of the participants feeling pressure to cooperate, voluntary participation was emphasized. Voluntary return of the completed survey constituted informed consent. Participants were protected through study approval by Grand Valley State University's Human Research Review Board (Appendix D). The researcher applied for expedited review. Risks to the subjects were considered minimal; however, psychological or emotional costs may have been present due to introspection or anger at the questions being asked as the subjects examined their lives. The cover letter included information about how to contact the renal
social worker if issues were raised which needed to be addressed. Risk due to fatigue, boredom, loss of time and physical discomfort were minimized by having the subjects complete the questionnaire on their own time, in the comfort of their own home. Approval to conduct this study was obtained by the Divisional Manager of Renal Care Group (Appendix E). In order to preserve confidentiality and the patient’s right to privacy, surveys were coded by number on return and not identified by the subject’s names. Identifying information was kept confidential and entered into the data base system. Identifying information was destroyed as quickly as possible when it was no longer needed. Results of the research were reported in the aggregate, therefore no individual identifiers were included in this paper.
The research question for this study was "What was the perceived quality of life (PQOL) for persons with end stage renal disease performing peritoneal dialysis?" Data analysis was accomplished using the statistical package for social sciences (SPSS/WIN) software. A level of significance at $p<0.05$ was established for all statistical procedures. Descriptive statistics were used to analyze general characteristics and demographic data. Perceived quality of life in an overall sense as well as in relation to each of the four domains of health and functioning, socioeconomic, psychological/spiritual and family was measured. Additionally, this study describes which dimensions within the four domains people were most satisfied with and which areas were perceived to be the most important.

Sixty-eight surveys were mailed or handed to subjects, and 31 were returned for a return rate of 45.5%. The distribution of gender was even with 15 (48.4%) males and 16 (51.6%) females. The ages of participants ranged from 30 – 83 years with a mean of 60.5 (SD=14.2). Participants had been receiving dialysis treatments of for a total of 2 –120 months ($M=26.2$, $SD=25.1$) Participants had been performing peritoneal dialysis (PD) from 1 – 91 months ($M=20.9$, $SD=18.1$). Participants were predominately Caucasian, 80.6%, with 12.9% African Americans, and 6.5% Native Americans. The majority of subjects (64.5%) were married, while 16.1% were widowed, 9.7% were divorced, and
3.2% were separated or never married.

The group was evenly divided with regard to the presence or absence of diabetes: 15 subjects (48.4%) had diabetes and 16 (51.6%) did not. The majority of subjects, 18 (58.1%) had never experienced peritonitis. Eight persons (25.8%) had experienced one episode of peritonitis and four (12.9%) had two episodes.

Perceived QOL

Ferrans’ and Powers’ Quality of Life-dialysis version (QOL-dv) was used to measure perceived quality of life overall. Additionally, the four domains of satisfaction with health and functioning, socioeconomic, psychological/spiritual, and family aspects of life were measured. The possible range for overall and subscale scores was 0 to 30 with higher scores indicating a better perceived QOL. Subject’s scores for overall QOL ranged from 12.18 to 29.77 with a mean of 24.88 (SD=3.90). Scores for health and functioning ranged from 12.23 to 29.83 with a mean of 24.84 (SD=3.91). Subjects rated their satisfaction with socioeconomic aspects between 12.17 and 29.64 with a mean of 24.95 (SD=3.75). Scores for psychological/spiritual aspects ranged from 12.0 to 30.0 with a mean of 25.36 (SD=3.88). For the last subscale, family, scores ranged from 12.33 to 30.00 with a mean of 20.08 (SD=3.88).

Satisfaction with Life Areas

Subjects rated, on a six point scale, their satisfaction with 35 areas in their lives. A rating of six represented very satisfied, while a rating of one was very dissatisfied. The top three areas that subjects were most satisfied with were the health care they received (M=5.55), the emotional support they receive from others (M=5.45), and their personal faith in
God (5.39). The 10 areas of most satisfaction are reported in Table 1.

Table 1

**Ranking of Areas of Satisfaction**

<table>
<thead>
<tr>
<th>Areas of satisfaction</th>
<th>Rank</th>
<th>Mean</th>
<th>Std. Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care they are receiving</td>
<td>1</td>
<td>5.55</td>
<td>0.62</td>
</tr>
<tr>
<td>Emotional support from others</td>
<td>2</td>
<td>5.45</td>
<td>0.72</td>
</tr>
<tr>
<td>Personal faith in God</td>
<td>3</td>
<td>5.39</td>
<td>0.95</td>
</tr>
<tr>
<td>Dialysis treatment</td>
<td>4</td>
<td>5.37</td>
<td>0.72</td>
</tr>
<tr>
<td>Their children</td>
<td>5</td>
<td>5.30</td>
<td>1.23</td>
</tr>
<tr>
<td>Relationship with spouse/significant other</td>
<td>6</td>
<td>5.21</td>
<td>1.22</td>
</tr>
<tr>
<td>Family’s health</td>
<td>7</td>
<td>5.14</td>
<td>0.93</td>
</tr>
<tr>
<td>Neighborhood</td>
<td>8</td>
<td>5.13</td>
<td>0.94</td>
</tr>
<tr>
<td>Home</td>
<td>9</td>
<td>5.10</td>
<td>0.84</td>
</tr>
<tr>
<td>Standard of living</td>
<td>10</td>
<td>4.90</td>
<td>0.92</td>
</tr>
</tbody>
</table>

**Important of Life Areas**

Subjects rated the areas of life with regard to perceived importance. The top three areas rated most important were their family’s happiness (M=5.81), their children (M=5.79), and their dialysis treatment (M=5.77). The ten areas that subjects rated most important are reported in Table 2.
Table 2

Ranking of Areas of Importance

<table>
<thead>
<tr>
<th>Areas of Importance</th>
<th>Rank</th>
<th>Mean</th>
<th>Std. dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family’s happiness</td>
<td>1</td>
<td>5.81</td>
<td>0.48</td>
</tr>
<tr>
<td>Children</td>
<td>2</td>
<td>5.79</td>
<td>0.63</td>
</tr>
<tr>
<td>Dialysis treatment</td>
<td>3</td>
<td>5.77</td>
<td>0.43</td>
</tr>
<tr>
<td>Health care</td>
<td>4</td>
<td>5.77</td>
<td>0.43</td>
</tr>
<tr>
<td>Happiness</td>
<td>5</td>
<td>5.77</td>
<td>0.50</td>
</tr>
<tr>
<td>Family’s health</td>
<td>6</td>
<td>5.74</td>
<td>0.63</td>
</tr>
<tr>
<td>Relationship with spouse/significant other</td>
<td>7</td>
<td>5.74</td>
<td>0.59</td>
</tr>
<tr>
<td>Physical independence</td>
<td>8</td>
<td>5.70</td>
<td>0.53</td>
</tr>
<tr>
<td>Home</td>
<td>9</td>
<td>5.70</td>
<td>0.65</td>
</tr>
<tr>
<td>Personal faith in God</td>
<td>10</td>
<td>5.60</td>
<td>0.89</td>
</tr>
</tbody>
</table>

Kidney Transplantation

Participants ranked their satisfaction with efforts toward a kidney transplant 25 of 35 (M=4.32). They ranked satisfaction with the potential for getting off dialysis 27 (M=4.04). Subjects ranked the level of importance of getting off dialysis 31 of 35 (M=4.78). They ranked importance of a successful kidney transplant as least important of the 35 areas (M=2.17).

Other Findings

After the data was analyzed descriptively, correlation between time on dialysis and QOL was looked at. The t-test was used to see if there was difference. There was a moderate correlation between the number of months on peritoneal dialysis and perceived QOL (r=.46, df=29, p=.012). Based on the t-test there was not a significant difference in overall QOL or in any of the four dimensions based on gender or the presence/absence of diabetes.
Discussion of Findings

This descriptive study assessed the perceived quality of life (PQOL) of 31 patients performing peritoneal dialysis (PD) independently in their homes. The sample was drawn from a group of 68 patients from a for profit dialysis unit in a Midwestern city. The results of this study showed that patients performing peritoneal dialysis (PD) had a relatively high perception of their quality of life (QOL). This study supports the results of Evans et al. (1985). That study concluded that although subjects were not functioning, objectively, as well as people who were well, they were enjoying life. Evans et al. (1985) measured subjective QOL with three indicators: well being, psychological affect, and life satisfaction. One difference to note is that Evans et al. (1985) found no significant relationship between the time on dialysis and subjective indicators of QOL, whereas this study found a moderate positive correlation between the number of months on PD and perceived QOL.

The 1989 QOL study by Bremer, McCauley, Wrona and Johnson revealed the following findings. Although there was a slight reduction in objective and subjective rating of QOL measures, there was not the global reduction in reported QOL for patients with end stage renal disease that some might think. The present study supported the finding
that perceived QOL is relatively high for patients performing peritoneal dialysis.

The results of this study were also compared to those of Ferrans and Powers (1993) study involving patients receiving hemodialysis. Ferrans and Powers (1993) reported significant differences between the QOL subscales. The mean score for the family subscale was significantly higher than the means for the other three subscales: health and functioning, social and economic, and psychological/spiritual. Additionally, the mean score for the health and functioning subscale was significantly lower than the three other subscales. This study did not reveal any significant differences between the four subscales using a two-tailed t-test. Ferrans and Powers' results showed that the patients receiving hemodialysis treatments rated their perceived QOL as relatively high. This study of patients performing peritoneal dialysis supports those findings. Participants in this study rated overall QOL, as well as the four subscales, higher than the Ferrans and Powers subjects. It is not clear, however, what this difference might be attributed to. First, the modality of dialysis was different as this study included patients performing PD rather than hemodialysis. Additionally, the populations may not have been similar with regard to demographics, physical condition or other variables, which were not measured. The difference could also be due to the type of patients who would participate in a study.

The instrument used in this study combined a satisfaction component with an importance component. In areas that are very important, a higher rating of satisfaction equates to a higher QOL score. Patients reported that they were very satisfied with most aspects of life that were of most importance to them. The exceptions to this were their family's happiness and their physical independence. Those areas were ranked as very
important but had lower satisfaction scores. Satisfaction scores on these two items were still in the positive range with mean scores of 4.90 and 4.87, respectively. Table 3 shows the ten highest ranked areas of importance along with their satisfaction ratings. On the other hand, if a person rated their level of satisfaction low, this could negatively affect their QOL score. It would be essential to know if an area of low satisfaction was important. If important, the overall QOL score may be negatively affected. Table 4 shows the areas of least satisfaction and the accompanying importance ratings. Participants reported that the areas that they were least satisfied with were, for the most part, ranked lower in importance. The two exceptions to this were usefulness to others and financial independence. Satisfaction scores on these two items, however, were still in the satisfied range with mean scores of 4.04 and 4.33, respectively. One area of interest is the lack of importance associated with either getting off of dialysis treatment or efforts toward a successful kidney transplant. These two items were not included on the instrument used in the 1993 study by Ferrans and Powers; therefore, no comparison is possible. Subjects ranked satisfaction with their sex life as the lowest of all areas. However, they also ranked it as 34 of 35 in importance. This result is similar to the findings of Ferrans and Powers (1993) study.

Theoretical Framework

Betty Neuman's systems model (1995) was used as the framework for this study. The findings support Neuman’s notion that people are in constant change and in continuous interaction with their environment. Her model states that the person, as a system, constantly monitors self and makes adjustments, as needed, provided support
systems are in place. This ability to adjust is necessary in order to retain, attain, and maintain stability for optimal health.

Table 3

**Highest Ranked Areas of Importance and Satisfaction Ratings**

<table>
<thead>
<tr>
<th>Area</th>
<th>Importance Rank</th>
<th>Mean (SD)</th>
<th>Satisfaction Rank</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family's happiness</td>
<td>1</td>
<td>5.81 (0.48)</td>
<td>11</td>
<td>4.90 (1.21)</td>
</tr>
<tr>
<td>Children</td>
<td>2</td>
<td>5.79 (0.63)</td>
<td>5</td>
<td>5.30 (1.23)</td>
</tr>
<tr>
<td>Dialysis treatment</td>
<td>3</td>
<td>5.77 (0.43)</td>
<td>4</td>
<td>5.37 (0.72)</td>
</tr>
<tr>
<td>Health care</td>
<td>4</td>
<td>5.77 (0.43)</td>
<td>1</td>
<td>5.55 (0.62)</td>
</tr>
<tr>
<td>Happiness</td>
<td>5</td>
<td>5.77 (0.50)</td>
<td>14</td>
<td>4.79 (0.85)</td>
</tr>
<tr>
<td>Family's health</td>
<td>6</td>
<td>5.74 (0.63)</td>
<td>7</td>
<td>5.14 (0.93)</td>
</tr>
<tr>
<td>Relationship with spouse/significant other</td>
<td>7</td>
<td>5.74 (0.59)</td>
<td>6</td>
<td>5.21 (1.22)</td>
</tr>
<tr>
<td>Physical independence</td>
<td>8</td>
<td>5.70 (0.53)</td>
<td>12</td>
<td>4.87 (1.20)</td>
</tr>
<tr>
<td>Home</td>
<td>9</td>
<td>5.70 (0.65)</td>
<td>9</td>
<td>5.10 (0.84)</td>
</tr>
<tr>
<td>Faith in God</td>
<td>10</td>
<td>5.60 (0.89)</td>
<td>3</td>
<td>5.39 (0.95)</td>
</tr>
</tbody>
</table>

Table 4

**Lowest Ranked Areas of Satisfaction and Importance Ratings**

<table>
<thead>
<tr>
<th>Area</th>
<th>Satisfaction Rank</th>
<th>Mean (SD)</th>
<th>Importance Rank</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex life</td>
<td>35</td>
<td>2.96 (1.71)</td>
<td>34</td>
<td>4.23 (1.70)</td>
</tr>
<tr>
<td>Travel/vacation</td>
<td>34</td>
<td>3.17 (1.74)</td>
<td>29</td>
<td>5.03 (1.40)</td>
</tr>
<tr>
<td>To have a job</td>
<td>33</td>
<td>3.43 (1.83)</td>
<td>32</td>
<td>4.38 (1.63)</td>
</tr>
<tr>
<td>Conditions in the US</td>
<td>32</td>
<td>3.74 (1.51)</td>
<td>28</td>
<td>5.07 (1.02)</td>
</tr>
<tr>
<td>Happy old age/retirement</td>
<td>30</td>
<td>3.83 (1.42)</td>
<td>33</td>
<td>5.23 (1.38)</td>
</tr>
<tr>
<td>Leisure time activities</td>
<td>29</td>
<td>3.97 (1.54)</td>
<td>22</td>
<td>5.21 (0.74)</td>
</tr>
<tr>
<td>Usefulness to others</td>
<td>28</td>
<td>3.97 (1.49)</td>
<td>11</td>
<td>5.59 (0.57)</td>
</tr>
<tr>
<td>Potential for getting off dialysis</td>
<td>27</td>
<td>4.04 (1.79)</td>
<td>31</td>
<td>4.78 (1.74)</td>
</tr>
<tr>
<td>Financial independence</td>
<td>26</td>
<td>4.16 (1.44)</td>
<td>14</td>
<td>5.55 (0.74)</td>
</tr>
</tbody>
</table>
Neuman views stressors as intrapersonal, interpersonal and extrapersonal. They rated all of these areas as important, as discussed earlier. An example of an intrapersonal force that was rated as important was personal health. Examples of interpersonal forces that were rated as important were family's happiness and usefulness to others. Some areas of extrapersonal forces that were rated as very important were the dialysis treatment they received and their health care. No prior studies were found that used Neuman's model as a framework for the study of patients with end stage renal disease receiving peritoneal dialysis. The model provided an interesting framework for interpreting and analyzing the responses. The perception of observers is quite often that patients on dialysis have a compromised QOL. Neuman's model suggests, and is supported by this study, that the process of adaptation leads to the ability to retain, attain and maintain stability for optimal health. This may explain why the satisfaction level in those surveyed is actually quite acceptable.

Implications

Implications for nursing are based on Neuman's model. Neuman (1995) stated that nursing is concerned with the "reduction of potential or actual stressor reactions" (p. 221). Neuman (1995) recognized that there might be perceptual distortions between the client and the nurse. Nurses may believe that the person with ESRD on dialysis does not have a very high QOL. In this study, however, overall QOL is actually rated quite highly. One finding of importance to nursing is the positive correlation between time receiving dialysis and perceived QOL. The awareness that patients are able to adjust to changes, in
other words, they adapt, and a new equilibrium is established may help guide patients through the initial stages of dialysis. This information may be useful as nurses are counseling pre-dialysis clients and families about the dialysis experience. Nurses may also benefit from knowing that patients ranked their dialysis treatments and health care among the highest in areas of importance. Other areas that were rated highly pertained to family. This included children, family's health and relationship with spouse/significant other.

Nurses may practice primary prevention to assist the client in maintaining system stability. They can assist the client and their family in protecting the normal lines of defense and strengthen the flexible lines of defense. If a person's perception is that stressors are not a threat, they will be able to achieve balance and stability. In this study patients generally rated the areas that they were least satisfied with as less important. Therefore, a lack of satisfaction did not necessarily lower their perceived QOL.

Limitations

This study had a small sample size (n=31), which represented 45.5% of eligible participants. This study was limited to patients in one geographical area. This consisted of a Midwestern city and the surrounding areas served by the dialysis facility which participated in the study. One dialysis facility, alone, was included. The study included patients capable of self care performing their own PD only. Patients who were not able to perform their own dialysis treatments independently were not included in this study. Patients residing in extended care facilities were not included. The results, therefore, are not generalizable to the entire dialysis population. One recommendation would be to replicate the study in other groups of patients from multiple centers, receiving various
treatments for ESRD. This would include home hemodialysis and transplant as well as PD. A longitudinal study might also provide interesting information with regard to patients adapting to PD.

Suggestions for Research

One area to study further is the lack of importance of getting off dialysis or getting a successful kidney transplant. It would be interesting to study why these are not perceived as important. It could be that patients have adapted and are coping with lifelong maintenance on dialysis. It could also be due to fear or a lack of information regarding transplant as a treatment option. These two questions were not included in the Ferrans and Powers study on patients receiving hemodialysis. Further study of this finding could provide useful information with regard to the need for education and presentation of transplant as an option for treatment of ESRD. Another area for further research would be to look at the instrument with regard to the four subscales. In this study the four subscales were highly correlated which is in contrast to the 1993 study by Ferrans and Powers. Further use of this instrument with different groups of subjects could help to determine if the four subscales are measuring distinctly different aspects of QOL.

Summary

In conclusion, this study provided information regarding the perception of quality of life for a subset of the end stage renal disease population, patients performing peritoneal dialysis, independently, at home. The study found that this group believes that their quality of life is quite high. This supports previous research in this area. Patients rated their quality of life higher the longer they have been receiving dialysis. They do not rate the
need to get off dialysis or receive a kidney transplant as very important. They are satisfied with most areas of their life. They are not satisfied with their sex life but do not see it as very important. Further research is needed to add to the body of knowledge regarding patient's perceived quality of life. This study provides information to assist nurses in counseling and caring for patients and their families, as they contemplate or receive dialysis as a treatment for kidney failure.
Appendices
APPENDIX A

Ferrans and Powers Quality of Life Index (QLI)
**QUALITY OF LIFE INDEX*  
DIALYSIS VERSION**

**Part I.** 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.

<table>
<thead>
<tr>
<th>HOW SATISFIED ARE YOU WITH:</th>
<th>Very Dissatisfied</th>
<th>Moderately Dissatisfied</th>
<th>Slightly Dissatisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Dialysis treatment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. The health care you are receiving?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Your physical independence?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. The efforts being made to increase your potential for having a successful kidney transplant?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Your potential for getting off dialysis (for example, through a successful transplant or medical discovery)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Your potential to live a long time?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Your family's health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Your children?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Your family's happiness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Your relationship with your spouse/significant other?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Your sex life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Your friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. The emotional support you get from others?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Your ability to meet family responsibilities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Your usefulness to others?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. The amount of stress or worries in your life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Your home?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

(Please Go To Next Page)

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Page 1

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<table>
<thead>
<tr>
<th>HOW SATISFIED ARE YOU WITH:</th>
<th>Very Dissatisfied</th>
<th>Moderately Dissatisfied</th>
<th>Slightly Dissatisfied</th>
<th>Slightly Satisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Your neighborhood?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>20. Your standard of living?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>21. Conditions in the United States?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>22. Your job (if employed)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>23. Not having a job (if unemployed, retired or disabled)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>24. Your education?</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>25. Your financial independence?</td>
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<td>26. Your leisure time activities?</td>
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<td>27. Your ability to travel on vacations?</td>
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<td>28. Your potential for a happy old/age retirement?</td>
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<td>29. Your peace of mind?</td>
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<td>31. Your achievement of personal goals?</td>
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<td>32. Your happiness in general?</td>
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<td>33. Your life in general?</td>
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<td>34. Your personal appearance?</td>
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<td>35. Yourself in general?</td>
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Part II. 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.

<table>
<thead>
<tr>
<th>HOW IMPORTANT TO YOU IS:</th>
<th>Very Unimportant</th>
<th>Moderately Unimportant</th>
<th>Slightly Unimportant</th>
<th>Slightly Important</th>
<th>Moderately Important</th>
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<td>1. Dialysis treatment?</td>
<td>1 2 3 4 5 6</td>
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<td>2. Your health?</td>
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<td>3. Health care?</td>
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<td>4. Your physical independence?</td>
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<td>5. A successful kidney transplant?</td>
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<td>6. Getting off dialysis (for example, with a transplant or medical discovery)?</td>
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<td>7. Living a long time?</td>
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<td>8. Your family's health?</td>
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<td>9. Your children?</td>
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<td>10. Your family's happiness?</td>
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<td>11. Your relationship with your spouse/significant other?</td>
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<td>12. Your sex life?</td>
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<td>13. Your friends?</td>
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<td>14. Emotional support?</td>
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<td>15. Meeting family responsibilities?</td>
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<td>16. Being useful to others?</td>
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<td>17. Having a reasonable amount of stress or worries?</td>
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<td>18. Your home?</td>
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*Copyright 1984 C. Ferrans and M. Powers (Do not use without permission.)

This tool is being used with permission of the author.
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<td>20. A good standard of living?</td>
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<td>21. Conditions in the United States?</td>
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<td>22. Your job (if employed)?</td>
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<td>23. To have a job (if unemployed, retired, or disabled)?</td>
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APPENDIX B

Permission to use the QLI
November 10, 1994

Ms. Paula Armstrong-Uhle
6120 Torrington Road
Kalamazoo, MI 49009

Dear Ms. Armstrong-Uhle:

Thank you for your interest in the Ferrans and Powers Quality of Life Index (QLI). I have enclosed the dialysis version of the QLI and the computer program for calculating scores. I also have included a list of the weighted items that are used for each of four subscales: health and functioning, social and economic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate subscale scores and overall scores.

There is no charge for use of the QLI. You have my permission to use the QLI for your study. In return, I ask that you send me any publications of your findings using the QLI. Such reports are extremely important to me.

I would prefer that you would not publish the QLI in your thesis. In the past the inclusion of the instrument in theses unfortunately led to the use of the instrument by persons who never contacted me for permission. However, you do of course have my permission to provide your committee members with copies of the QLI in its entirety.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN
Assistant Professor
APPENDIX C

Letter to the Participants
Dear __________

Hello! I worked for many years with patients who are on dialysis. As a nurse, I am very interested in knowing how patients such as you are doing. Nurses and doctors can look at lab tests and reports and see how you are doing on dialysis, but I would like to know how you are doing in another way. That is, how does being on dialysis affect your quality of life?

I am conducting this study as part of my Masters of Nursing program at Grand Valley State University. Your opinions are needed in order to understand how patients on dialysis view their life. It is hoped that this information may help nurses and other health care providers gain a better understanding of what patients experience. While this study may not benefit you directly, it may be very helpful for us in assisting people to make decisions about their treatments.

Please do not put your name on the survey so that your responses will be anonymous and confidential. The results will not be reported by name but by groups of people only. It is not expected that participating will cause you harm in any way. If thinking about these issues upsets you or causes concern, the renal Social Worker will be available to assist you. You may call the dialysis unit and ask for her or ask your nurse to call her if you are in the clinic. If you agree to participate in this study, please complete the enclosed survey. I expect that it will take about 10 – 15 minutes to complete. You may return it in the enclosed self-addressed stamped envelope or just drop it in the box in the CAPD clinic. If you have any questions, please feel free to call me at Borgess. My phone number is (616) 226-7327.

Thank you very much for considering participating in this study. I am excited to find out what you are thinking.

Sincerely,

Paula Armstrong

Note: If you have questions about your rights as a subject in a research study, you may contact Paul Huizenga, Chair of the Human Research Review Committee for Grand Valley State University at (616) 895-2472.
APPENDIX D

Human Subjects Review Committee Approval
September 20, 1999

Paula Armstrong
6120 Torrington Road
Kalamazoo, MI 49009

Dear Paula:

Your proposed project entitled Perceived Quality of Life of Patients Performing Peritoneal Dialysis has been reviewed. It has been approved as a study which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

[Signature]

Paul A. Huizenga, Chair
Human Research Review Committee
APPENDIX E

Permission to Use Subjects
August 23, 1999

To whom it may concern,

Paula Armstrong has permission to conduct a study pertaining to her thesis “Perceived Quality of Life in Patients Performing Peritoneal Dialysis”. Renal Care Group will assist with her endeavor in whatever is necessary.

If you have any questions, please contact me at (616) 384-6180.

Sincerely,

Chris Longton
Divisional Manager
List of References
REFERENCES


Skeel, R. (1993). Quality of life dimensions that are most important to cancer patients. *Oncology, 7*, 55-70.