

1999

## Quality of Life of the Hemodialysis Patient

Tammy Bronson  
*Grand Valley State University*

Follow this and additional works at: <https://scholarworks.gvsu.edu/theses>



Part of the [Nursing Commons](#)

---

### ScholarWorks Citation

Bronson, Tammy, "Quality of Life of the Hemodialysis Patient" (1999). *Masters Theses*. 531.  
<https://scholarworks.gvsu.edu/theses/531>

This Thesis is brought to you for free and open access by the Graduate Research and Creative Practice at ScholarWorks@GVSU. It has been accepted for inclusion in Masters Theses by an authorized administrator of ScholarWorks@GVSU. For more information, please contact [scholarworks@gvsu.edu](mailto:scholarworks@gvsu.edu).

QUALITY OF LIFE OF THE HEMODIALYSIS PATIENT

By

Tammy Bronson

A THESIS

Submitted to  
Grand Valley State University  
in partial fulfillment of the requirements for the  
degree of

MASTER OF SCIENCE IN NURSING

Kirkhof School of Nursing

1999

Thesis Committee Members:

William C. Baum, Ph.D.

Kay Setter Kline, Ph. D. ,R. N.

Kay Reick, M. S. , R. N.

## ABSTRACT

### QUALITY OF LIFE OF THE HEMODIALYSIS PATIENT

By

Tammy Bronson

There are over 250,000 people currently afflicted with end-stage renal disease and the number is rising every year. Although kidney transplant is the treatment of choice, lack of viable organs limits this option. Hemodialysis is the most common treatment modality for end stage renal disease. Quality of care is continuously monitored by physicians, nurses and dietitians, however there is also the need to examine the quality of life of the hemodialysis patient. This study replicated the works of Ferrans and Powers (1993).

Overall quality of life and four subscales (health and functioning, social and economic, psychological/spiritual, and family) were evaluated by using the Quality of Life Index. Overall quality of life of a small sample of hemodialysis patients was subjectively rated as relatively high, with the most satisfaction noted in the family subscale.

## Table of Contents

List of Tables.....	iv
List of Figures .....	v
List of Appendices .....	vi
CHAPTER	
1 INTRODUCTION .....	1
2 LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK .....	4
Review of Literature .....	4
Conceptual Framework .....	9
Research Question .....	12
3 METHODOLOGY .....	14
Sample and Setting .....	14
Instrument .....	16
Procedure .....	17
4 RESULTS .....	18
Research Question .....	19
Subsequent Findings .....	19
5 DISCUSSION AND IMPLICATIONS .....	21
Limitations and Recommendations .....	23
Implications for Nursing .....	23
REFERENCES .....	26

## List of Tables

### TABLE

1	Elements of Ferrans Conceptual Model for Quality of Life .....	11
2	Sample characteristics .....	15
3	Overall Quality of Life Scores and Subscale Scores .....	19
4	Correlation Coefficients .....	20

## List of Figures

### FIGURE

- 1 Hierarchical relationships between the global construct of quality of life, four major domains, and specific aspects of the domain .....13

## List of Appendices

### APPENDIX

A	Demographic Data Form.....	29
B	Quality of Life index.....	31
C	Reliability and Validity of the Ferrans and Powers Quality of Life index.....	35
D	Cover Letter.....	39
E	Informed Consent.....	40
F	Scoring Procedure for the Quality of Life index.....	41
G	Authorization to use copyrighted material.....	44
H	Human Subjects Research Approval .....	46

## CHAPTER 1

### INTRODUCTION

There are over 250,000 people currently afflicted with end-stage renal disease (ESRD), and the number is rising at about 7% every year (United States Renal Data System, 1997). The disease affects all ages, but the majority of patients are between the ages of 20 and 64. It is slightly more common in males than females and has the highest prevalence in Blacks followed by Native Americans, Asian Pacific Islanders, and Whites. The most common causes of ESRD are diabetes and hypertension. The treatment of choice for many patients with ESRD is kidney transplant. Unfortunately, the scarcity of viable organs as well as comorbid conditions place transplant surgery beyond the reach of most patients (Sosa-Guerrero & Gomez, 1997). Hemodialysis is the most common treatment modality used for end-stage renal disease (United States Renal Data System, 1997).

Current medical knowledge and experience have made it clear that we can prolong the lives of those people experiencing end-stage renal disease. The hemodialysis treatment actually is able to remove many of the toxins present in the blood of the ESRD patient, but unfortunately it is unable to remove all of the toxins (Nissenson, Fine & Gentile, 1995). The ESRD patient therefore remains in a constant state of uremia and is never able to regain full health. To assist the ESRD patient in achieving higher levels of health, the healthcare provider must evaluate the current treatment plan, assess the quality



of care and implement new treatments if necessary. Objective data such as serum urea, calcium, phosphorous, potassium and intradialytic weight gain have been given defined parameters of acceptability by the ESRD Network and the Health Care Financing Administration (HCFA). They are easily measured and evaluated. Quality of care, however may not be synonymous with quality of life.

There have been numerous studies evaluating the quality of life of patients with chronic disease. While there is considerable debate about the conceptualization and measurement of quality of life, there does seem to be general agreement that quality of life is multidimensional and subjective (Molzahn, Northcott, & Dossetor, 1997; Ferrans & Powers, 1993). In studies in which the quality of life was evaluated by objective measurements, including assessments based on interviews, psychological tests, and lab values, a fair-to-poor quality of life was reported (Kaplan De-Nour & Shanan, 1980). In contrast, studies in which patients subjectively evaluated their lives, quality of life has been reported to be relatively good (Ferrans & Powers, 1993; Meers, et al, 1995).

There is a need to examine specific areas that may affect the quality of life of the hemodialysis patient. Four domains of life have been described as being important to the quality of life of any individual. These domains include health and functioning, social and economic, psychological/spiritual, and family (Ferrans & Powers, 1993). Information obtained about these areas would allow the health care provider to identify problem areas, examine current practices, facilitate communications with the patient and plan interventions that would improve quality of life. The purpose of this study was to assess the quality of life of the hemodialysis patient and obtain information about specific

domains of life, including health and functioning, social and economic, psychological/spiritual and family, which may have affected their quality of life.

## Chapter 2

### Literature and Conceptual Framework

#### Review of Literature

Quality of life is a central concern in evaluative research; improved quality of life is probably the most desirable outcome of all health care policies (Farquhar, 1995). The term quality of life is used extensively in research studies, however, the conceptualization of the term remains ambiguous among researchers. Farquhar (1995) developed a classification of the quality of life definitions that demonstrated the lack of consensus but also organized the existing definitions into a framework that identified common elements. Four types of definitions for the term quality of life can be illustrated from an extensive review of the literature: (a) global, (b) component, (c) focused, and (d) combination.

Global definitions seem to be the most common type of definition of the concept of quality of life. These definitions are all encompassing and usually incorporate the ideas of satisfaction/dissatisfaction and happiness/unhappiness. Dorfman (1995) defined quality of life as “satisfaction, a sense of well-being indicating how the individual perceives his or her quality of life” (p. 192). Mast (1995) indicates the quality of life is “what makes life worthwhile”(p. 957). Dale (1995) states the “meaning and value our lives hold are expressed in terms of our individual view of quality of life” (p. 1134). Unfortunately, because of the generality, these definitions tell us little about the components of the concept and make it difficult to operationalize.

Component definitions are those which break quality of life down into a series of component parts or dimensions, or identify certain characteristics deemed essential to any evaluation of quality of life (Farquhar, 1995). These definitions can become research specific by focusing the concept of quality of life to the area of interest. An example of this would be a study done by Ferrans and Powers (1993). They globally define quality of life as “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him or her” (p. 516), but then conceptualize the term further by utilizing a multidimensional construct that consists of four major life domains including health and functioning, social and economic, psychological/spiritual, and family. Morgan (1990) also related quality of life to “life satisfaction and well-being” but listed specific domains that were felt to be related to subjective well-being.

Focused definitions of quality of life are those which refer to only one or a small number of the components of quality of life (Farquhar, 1995). These definitions are commonly found in papers that use the term “health-related quality of life”. Meers, et al. (1995) did a comparison of patient, nurse, and physician assessment of health related quality of life in end-stage renal disease. The tools utilized for this study to determine quality of life focused only on health related items. Wolcott, Nissenson and Landsverk (1988) published their study, “Quality of Life in Chronic Dialysis Patients” using the term “quality of life” and “adaptation” interchangeably. This made it difficult for the reader to fully interpret the meaning of the term.

Finally, many authors utilize a combination of the definitions. Burrows-Hudson (1995) published an article describing nephrology clinical outcomes. She states that

“health-related quality of life emphasizes physical, psychological and social functioning as well as satisfaction with health” (p. 119).

For the purpose of this study, review of the literature focused specifically on the quality of life of the hemodialysis patient. Evaluation of quality of life could be attempted in one of two ways, objective assessments done by the interviewer or subjective assessments completed by the patients themselves. The findings from these two methods appear to be quite different.

In 1985 Evans et al. published a study which assessed the quality of life of patients with end-stage renal disease. A survey was completed in 11 dialysis and transplant centers throughout the United States and was inclusive of 859 patients. Data were collected from medical records and health care professionals familiar with the patients. Personal interviews were conducted by trained interviewers. Four major categories of variables were analyzed: sociodemographic, medical, objective indicators of quality of life which included functional impairment and ability to work, and subjective indicators of quality of life which included well-being, psychological affect and life satisfaction. Primary diagnosis, comorbidity, length of time on current treatment and history of failed transplant were also considered to be relevant variables. Tools utilized included the Karnofsky Index, the Index of Psychological Affect, the Index of Overall Life Satisfaction and the Index of Well Being (as cited in Evans, et al. 1985). There was no mention in the article related to the validity of these tools. The results of this study indicated that patients with end-stage renal disease have a poor objective quality of life but subjectively rated their quality of life as being much higher.

In another study, Molzahn, Northcott, and Dossetor (1997) described the perceptions of physicians, nurses and patients regarding the quality of life of the individual with end-stage renal disease. The sample included 215 patients, 42 nurses, and 7 physicians. All were from a major tertiary hospital in western Canada. A cross-sectional, descriptive comparative design was used with three tools utilized to measure quality of life. These included the Self-Anchoring Striving Scale, the Index of Well-Being and the Time Trade Off (as cited in Molzahn, Northcott, and Dossetor, 1997). Each tool was well described with relevant validity and reliability information. The results of this study revealed that the nurses' and the physicians' ratings of the patient's quality of life were much lower than were the patients' ratings of themselves. Limitations of this study included lack of random sampling, small sample size of the caregivers, and low stability reliability of some of the independent variables. In general, it appears that in studies where patients subjectively evaluate their lives, quality of life is relatively good (Bihl, Ferrans, & Powers, 1988; Evans, et al, 1985; Ferrans & Powers, 1993; Wilcott, Nissenon, & Landsverk, 1988).

Some investigators have attempted to describe specific variables that might affect perceived quality of life. Morgan (1990) published his study on the relationship of chronological age and perceived quality of life of the hemodialysis patient. He used a small sample of 17 male patients from a Veteran's Administration Hospital. The Quality of Life Index (Ferrans and Powers, 1993) was utilized. No statistically significant correlation was found between age and quality of life. Limitations of this study included the small sample size, lack of randomization, and the use of a convenience sample.

Molzahn et al., (1997) did not find statistical correlation between age and quality of life but did find statistical significance in the variables of treatment modality, “outlook”, and morbidity as measured by the number of hospitalizations. Contradicting these results were the findings of a study published by Bihl, Ferrans, and Powers (1988) which did not find significant difference in the quality of life ratings between the differing treatment modalities of continuous ambulatory peritoneal dialysis (CAPD) patients and hemodialysis patients.

The lack of specific definitions of quality of life in most studies makes it difficult to obtain useful information that could be incorporated into nursing activities to improve or enhance patient quality of life. Ferrans and Powers (1993) published their study of quality of life of the hemodialysis patient and provided the reader with a clear understanding of their definition of quality of life utilizing a framework that broadened the understanding of the concept. The study was an exploratory descriptive design in which 349 randomly selected hemodialysis patients in the state of Illinois were mailed a questionnaire. The tool utilized was the Quality of Life Index that was developed by Ferrans & Powers in 1985. Reliability and validity of this tool were well documented (Ferrans and Powers, 1993). Quality of life 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 or her” (Ferrans and Powers, 1993, p. 516). The framework utilized was one that was developed by Ferrans (1990) in which “quality of life is conceptualized as a multidimensional construct that consists of four major life domains: health and functioning, social and economic, psychological/spiritual, and family” (p. 15). The findings of this study revealed that the mean score for the family subscale was

significantly higher than the means for the other three subscales. The mean scores for the health and functioning subscales were significantly lower than the means for the other subscales. In general, the subjects were satisfied with the areas of life that were the most important to them.

In conclusion, quality of life remains an ambiguous term for most authors which makes it difficult to operationalize the concept into nursing practice. Yet quality of life is a critically important concept for all of health care. It has been implicated in decisions to implement or stop life-sustaining medical treatments. Debates regarding physician-assisted suicide often involve quality of life considerations and the concept also is used in decisions pertaining to allocation of health care services. The conceptual model developed by Ferrans (1996) provides both the researcher and the reader with a clear understanding of the concept.

### Conceptual Framework

The conceptual framework that served as a basis for this study was the model developed by Ferrans (1996). Realizing the importance of quality of life in health care, Ferrans wanted to develop a tool that would allow easy measurement of this concept. Conceptual clarity, however, was not readily apparent. Literature review revealed a wide variety of meanings for the term quality of life. A concept is “a complex mental formulation of empiric perceptions of the world” (Chinn and Kramer, 1991, p. 80). Creating conceptual meaning allows one to understand what is exactly intended so that misunderstandings about meanings can be avoided. It produces a tentative definition of the concept. Ferrans began concept analysis utilizing a variety of approaches including review of the literature, qualitative methodologies and quantitative methodologies. She



selected an ideologic approach of the individualistic view in which individuals personally define what quality of life is for them. This approach recognizes that different people value different things.

Further examination of the literature revealed that there were six major conceptualizations of quality of life: the ability to live a normal life, ability to live a socially useful life, natural capacity, achievement of personal goals, happiness/affect, and satisfaction with life (Ferrans, 1996). Ferrans believed that conceptualizing quality of life with satisfaction was the most congruent with the individualistic approach. Satisfaction is a cognitive experience based on a person's judgment of life's conditions. It has been conceptualized as "an assessment of life as a whole, based on the fit between personal goals and achievement" (Ferrans and Powers, 1992). Quality of life is 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, 1996). This definition takes into consideration that due to cultural, ethnic, and religious values, different people value different things (Ferrans and Powers, 1992).

In order to determine the content of quality of life Ferrans (1996) used qualitative analysis to obtain a list of 32 elements that were associated with quality of life for the general population. These elements were then clustered into four different domains using factor analysis (see Table 1). External validation of the conceptual model was provided by the work of Ferrell, Grant, Padilla (1991) and their colleagues (Ferrell, Dow, Leigh, Ly, and Gulasekaram, 1995; Ferrell, Wisdom, and Wenzl, 1989; Padilla, Ferrell, Grant, and Rhiner, 1990). They completed a similar study during the same period of time developing a conceptual model of quality of life based on qualitative analysis of data

*Quality of Life*

TABLE 1. Elements of the Ferrans Conceptual Model for Quality of Life

<i>Health and Functioning Domain</i>	<i>Social and Economic Domain</i>
Usefulness to others	Standard of living
Physical independence	Financial independence
Ability to meet family responsibilities	Home (house, apartment)
Own health	Neighborhood
Pain	Job/Unemployment
Energy (fatigue)	Friends
<i>Stress or worries</i>	Emotional support from others
Control over own life	Education
Leisure time activities	
Potential for a happy old age/retirement	<i>Family Domain</i>
Ability to travel on vacations	Family happiness
Potential for a long life	Children
Sex life	Relationship with spouse
Health care	Family health
<i>Psychological Spiritual Domain</i>	
Satisfaction with life	
<i>Happiness in general</i>	
Satisfaction with self	
Achievement of personal goals	
Peace of mind	
Personal appearance	
Faith in God	

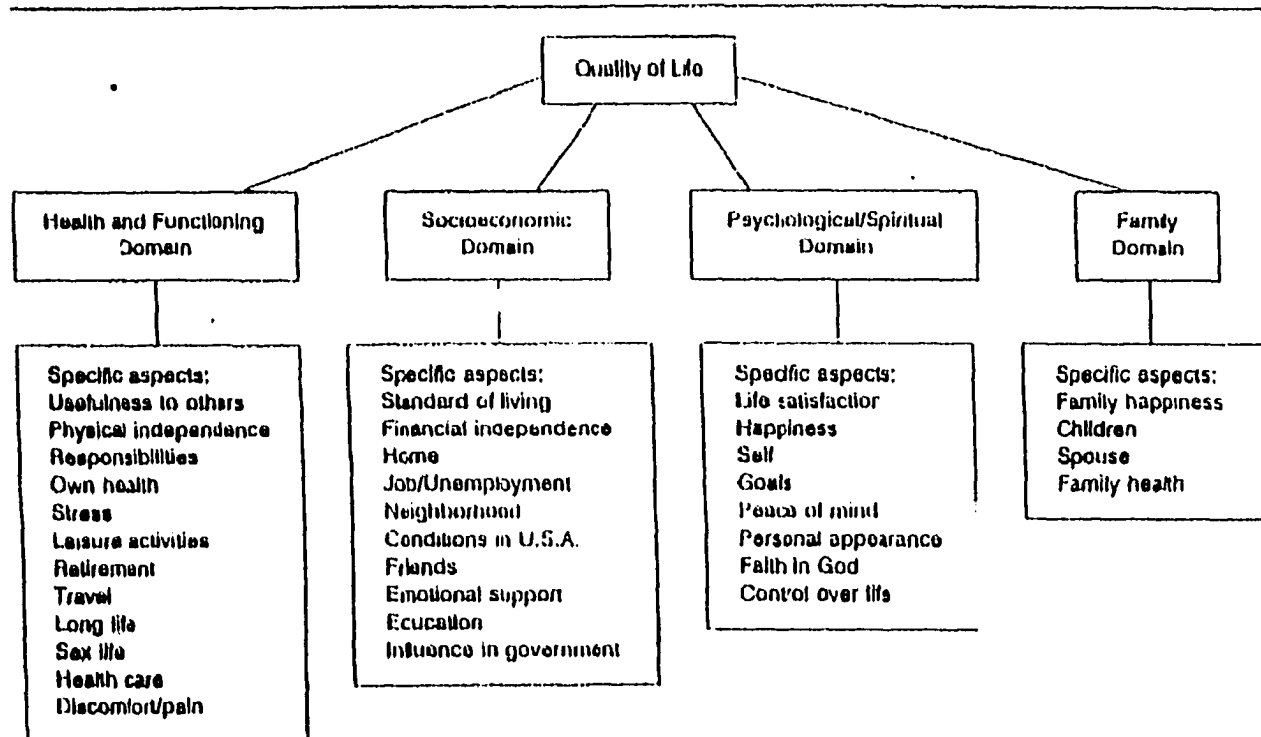
Note. From "Development of a Conceptual Model of Quality of Life" by C. E. Ferrans, 1996, Scholarly Inquiry for Nursing Practice: An International Journal, 10, p. 295. Copyright 1996 by Springer Publishing Company. Reprinted with permission

from cancer patients. The close match between the models provided mutual validation of the two models.

The final model of quality of life appears as shown in Figure 1. It is represented as having four major underlying domains and these domains include 35 aspects of life. It is a multidimensional construct. The use of this model offers the reader an understanding that there are many areas that may affect a person's subjective feelings of quality of life. Each individual may value different areas with different levels of importance at different times of their lives. Ferrans utilized this model in developing the Quality of Life Index which asks a series of questions related to the elements defined as being important to quality of life. The questions are asked in a two part format in which one question will determine the level of satisfaction or dissatisfaction with an element and the second will determine the importance of that element. The division of the elements into specific domains allows the researcher to focus on areas in which there is a high priority but low satisfaction.

### Research Question

Quality of life is an important issue for all health care providers. The specific research question for this descriptive study was "what is the subjective quality of life of the hemodialysis patient at a small southwestern Michigan dialysis center?" The specific aims were to assess quality of life overall and in specific domains: health and functioning, social and economic, psychological/spiritual, and family.



**Figure 1. Hierarchical relationships between the global construct of quality of life, four major domains, and specific aspects of the domain.**

Note: From "Development of a quality of Life Index for Patients with Cancer" by C. E. Ferrans, 1990, *Oncology Nursing Forum*, 17, p. 16. Reprinted with permission.

## Chapter 3

### METHODOLOGY

The goal of this research study was to describe the subjective quality of life of the hemodialysis patients at a southwestern Michigan dialysis center. This was accomplished by utilizing a simple descriptive design. All outpatient chronic hemodialysis patients who could speak and understand English were given the opportunity to complete the Quality of Life Index, Dialysis Version (Ferrans & Powers, 1984). General data information were obtained from each patient by a written demographic information form (Appendix A).

#### Sample and Setting

Upon approval of the appropriate committees, the Quality of Life Index questionnaire was offered to all chronic hemodialysis patients who were dialyzed at the outpatient hemodialysis center chosen for this study. This target population consisted of 94 patients who were dialyzed between 2 and 3 times per week. A total of 40 questionnaires were completed for a return rate of 44%.

The typical patient of the final sample was a married, white male, approximately 59 years of age. The following table summarizes the entire sample.

Table 2 sample characteristics

Variable	Sample
Age in years	Mean = 59.73 years Range = 25-84 years
Gender	Male = 60% Female = 40%
Race	White = 60% Black = 35% Hispanic = 2.5% Asian = 2.5%
Marital status	Married = 60% Single = 17.5% Divorced = 10% Widowed = 12.5%
Education	High school = 65%
Employment	Full time = 2.5% Unemployed = 12.5% Disabled = 27.5% Retired = 57.5%
Income level	< \$5,000 = 5% \$5,000-\$9,999 = 20% \$10,000-\$14,999 = 17.5% \$15,000-\$19,999 = 20% \$20,000-\$24,999 = 2.7% >\$25,000 = 27.5% no response = 7.5%

The mean time on dialysis was 42.4 months with a range from 2 months to 168 months (SD= 39.6 months). The most common cause of renal failure was hypertension (37.5%) followed by diabetes (25%) and glomerulonephritis (10%). Fifteen percent of the sample stated other causes of their renal failure and 12.5% were unsure what caused their renal failure. Eighty five percent of the sample listed hypertension as a comorbid condition.

The outpatient hemodialysis unit is an 18 station unit located in a small urban community in southwestern Michigan. The unit is divided into three separate treatment areas which allow for dialysis of 6 patients at a time in each area. The unit is staffed by

RN's, LPN's, and patient care technicians. The staff to patient ratio is approximately 1 to 2-4. The unit also provides a full time dietitian and 2 part time social workers. A physician is available for consultation at all times.

### Instrument

The Quality of Life Index (Ferrans & Powers, 1984, See Appendix B) is a 64-item tool composed of two parts. The first part measures satisfaction with four domains of life including health and functioning, psychological/spiritual, social and economic, and family. The second part measures the importance of the same domains of life. The tool uses a 6 point Likert type scale in part one where 6 is very satisfied and 1 is very dissatisfied. In part two the 6 point Likert type scale is also utilized with 6 being very important and 1 being very unimportant. The overall quality of life scores can then be calculated by weighting each satisfaction response with its paired importance response. The weighting of scores provides information that will reflect the individual's values as well as their satisfaction. The high scores obtained will be from those items that are marked as being of high satisfaction and high importance. The lowest scores will be those items that are marked as being high dissatisfaction and high importance. This weighting scheme is utilized because of the belief that people who are highly satisfied with areas of life they value enjoy a better quality of life than those who are very dissatisfied with the areas they value (Ferrans, 1990).

Consistency and reliability information on the Quality of Life Index has been published by numerous authors. A summary has been provided by Dr. Ferrans (See Appendix C). Internal consistency reliability for the total Quality of Life index was supported for this study by Cronbach's alpha equal to 0.9336. The health and function

subscale had an alpha of .8382, the social and economic subscale had an alpha of .7511, the psychological/spiritual subscale was .8963, and the family subscale had an alpha of .8251.

### Procedure

Upon approval from the institutional review board, a packet which included a cover letter ( Appendix D), informed consent (Appendix E ), demographic questions (Appendix F), and the Quality of Life Index was distributed to all chronic hemodialysis patients who were routinely dialyzed at the chosen center and were able to read and understand English. For those patients who were unable to read, an assistant was available to read the questions to them. The packets were distributed by the investigator on Wednesday and Thursday of the week designated for the study. The cover letter described the study and the procedure. The informed consent offered the subject the right to refuse to participate in the study. Informed consent was assumed if subjects complete the questionnaire and returned it.

When the questionnaires were completed the subjects placed them in the packet envelope and returned it to a designated area within the dialysis unit. All packets accepted for the study were returned at the completion of each individual's dialysis session.



## Chapter 4

### RESULTS

The purpose of this research project was to describe the subjective quality of life of the hemodialysis patient currently being dialyzed at a small southwestern Michigan dialysis center. Data analysis began after all surveys had been completed. Overall Quality of Life Index scores and subscale scores were calculated as described by Dr. Ferrans (See Appendix F). Data were analyzed using the Statistical Package for the Social Sciences (SPSS). Pearson r correlation coefficients were used to determine relationships between the interval level variables. Acceptable significance level was set at  $p < .05$ .

Demographic variables were explored to determine whether certain groups of patients had higher perceived quality of life. The overall quality of life score was the dependent variable and the following were the independent variables: age, race, sex, marital status, employment, education level, income level, number of years on dialysis, and comorbid conditions.

The first step in analyzing the data was to determine a strategy for dealing with missing data. Polit and Hungler (1995) suggest deleting a question if a large number of subjects have left it unanswered. Question #21 in the Quality of Life Index asked "how satisfied are you with your job". Twenty-two of the forty respondents left this question unanswered. The demographic information of this sample revealed that 97.5% were

either unemployed, disabled, or retired. It was felt that this question should be deleted. The scoring procedure utilized for obtaining total scores included steps to eliminate bias secondary to missing data.

Research Question

What is the subjective quality of life of the hemodialysis patient? The mean scores for the overall quality of life and the four subscales are reported in Table 2.

Table 3

Overall Quality of Life Scores and Subscale Scores

Scale	Mean	SD	Range*
Overall Quality of life	21.37	4.48	9.6 - 28.2
Family subscale	23.93	4.88	12.5 - 30.0
Social and economic subscale	23.06	4.61	11.9 - 30.0
Psychological/spiritual subscale	22.45	7.15	7.0 - 30.0
Health and functioning subscale	19.34	4.95	5.2 - 27.0

\* The range possible for the overall score and each subscale score was 0 to 30.

Subsequent Findings

Pearson r correlation coefficients were then examined to determine if any relationship existed between the interval level variables of age, education and time on dialysis to the overall quality of life and each of the four subscales. Significant correlation ( $p < .05$ ) was noted between the family subscale and age ( $p = .04$ ), the family

subscale and education ( $p = .007$ ), the psychological/spiritual subscale and education ( $p = .047$ ) and between the social and economic subscale and age ( $p = .006$ ). Results are noted in Table 3.

Table 4

Correlation Coefficients

---

	AGE	ED	TIME
QOL	ns	ns	ns
FAMILY	.3232 p=.042	-.4168 p=.007	ns
HEALTH	ns	ns	ns
PSYCH	ns	-.3164 p=.047	ns
SES	.4304 p=.006	ns	ns

---

ns = not significant

## CHAPTER 5

### DISCUSSION AND IMPLICATIONS

What is the subjective quality of life of the hemodialysis patient at a small southwestern Michigan dialysis unit? This research project attempted to answer that question by replicating a study done by Ferrans and Powers (1993). Reliability of the tool was supported with Cronbach's alpha of 0.9336 for the Quality of Life Index.

Forty hemodialysis patients completed the Quality of Life Index. This sample, although small, represented a reasonable match to the hemodialysis population in general. Relatively high mean scores (range 19.34 -23.93) were found for the overall quality of life and for the four subscales. Ferrans and Powers (1993) reported that the mean score for a group of healthy persons using the general population version of the same instrument was 21.9. The hemodialysis patients from this study scored just slightly lower with a mean of 21.37. Quality of life mean scores were highest in the family domain and lowest in the health and functioning domain. This indicates that these patients were more satisfied with the things that they valued in the family domain than in the other three domains. Ferrans and Powers also reported high degrees of satisfaction with family. This may be related to the fact that when a patient starts dialysis it usually requires the assistance and support of family and friends. Renal failure with resulting hemodialysis requires the adjustment of time schedules, transportation issues, as well as

dietary and lifestyle changes. Family support becomes of utmost importance if the dialysis patient is to adjust to this new lifestyle. The lowest mean scores fell in the health and functioning domain. It is not surprising that this was the lowest area of satisfaction. Campbell, Converse, and Rodgers (1976) found that poor health had the greatest impact on quality of life when it prevented people from doing what it was they wanted to do. The hemodialysis treatment in and of itself can cause a great deal of interference with people's lives. The treatment is time consuming and often leaves the patient feeling drained of energy after the treatment is completed. Although the dialysis treatment is a life sustaining treatment, it requires a significant amount of adaptation and adjustment by the patient to maintain a sense of satisfaction about their health and functioning.

Relationships between demographic variables and quality of life were explored. Significant correlation was noted between age and family ( $r = .3232$ ,  $p = .04$ ) and age and social/economic subscales ( $r = .4304$ ,  $p = .006$ ). This indicated that for this sample the higher the age, the higher the level of satisfaction with family and social and economic status. This may be because the older dialysis patient felt that they had already been able to achieve some of their goals related to family and social and economic areas, where as younger dialysis patients had not had that opportunity secondary to their health status. Significant correlation was also noted between family and education ( $r = -.4168$ ,  $p = .007$ ). This indicating that decreased years of education was associated with increased satisfaction with family. Finally, education and psychological/spiritual subscales demonstrated significant correlation, again with decreased years of education being associated with increased satisfaction in the psychological/ spiritual subscale. It could be surmised that those who had higher education levels experienced decreased

satisfaction because they were unable to achieve their goals secondary to their disease process and the hemodialysis treatment.

### Limitations and Recommendations

The small nonprobability convenience sample (N = 40) and single institution setting were limitations to this study. This prohibits any generalizations beyond the study sample. History may have posed a threat in that the dialysis unit had just recently been sold to a private company and many changes were in process when this survey was conducted. The generalizability of the results from this study to other populations could be facilitated by the use of random sampling, increasing sample size and using multiple dialysis centers.

### Implications for Nursing

Quality of care is routinely assessed for all hemodialysis patients by their physicians, dietitians and nurses. Changes are routinely made to maintain a standard of care. Quality of life could also be assessed and addressed for each patient by utilizing the Quality of Life Index. It is important for nurses to understand the factors that could predict the quality of life of a patient. Are there areas where we could promote satisfaction and thereby improve quality of life? Would patients be more willing to accept the dietary restrictions and the hemodialysis treatment time requirement if there was increased satisfaction in the health subscale?

An area of consideration that the caretaker must consider is the issue of existence. A person diagnosed with renal failure is forced to make a literal life and death decision. Life being supported with dialysis treatments three times a week or death if no treatment is initiated. When the patient chooses to start dialysis they have in effect chosen to live.

Therefore, life in itself must contain a certain level of quality. That “quality” can truly only be measured by the patient.

The conceptual framework developed by Ferrans (1996) stated that people are individuals. Quality of life could only be defined for a person by that person. The dialysis patients who completed this survey were able to conceptualize their quality of life by clearly stating which areas of their life that were important to them and how satisfied they were with that area.

Quality of life needs to be as closely examined as quality of care for the hemodialysis patient. Further research and education are needed so that clinicians can obtain better data to facilitate assignment of patients to treatment approaches that will enhance their quality of life. Areas of research that might benefit improved quality of life might include the effects of family involvement in patient care, the changes in self esteem associated with “self-care” hemodialysis, or improvements in quality of life associated with formal exercise programs. Studying the possible association between the grief process and the first year of hemodialysis might reveal areas that nurses could anticipate and therefore assist with coping strategies.

Nurses and administrators must continue to explore this area of quality of life. It was not that long ago when committees of people decided whether one would be allowed to have dialysis or not. Governmental funding now allows anyone with renal disease to receive hemodialysis. This has become a large allocation of limited healthcare resources and very well might become more “controlled” in the upcoming years.

Ferrans (1996) developed a conceptual framework that allows the clinician to obtain specific information from patients about their subjective feelings of their quality of

life. This information obtained from the Quality of Life Index could easily be used to examine current practices, facilitate communications and plan for interventions that would improve the quality of life of the hemodialysis patient.



## List of References

Bihl, M. A. , Ferrans, C. E. , & Powers, M. J. (1988). Comparing stressors and quality of life of dialysis patients. American Nephrology Nurses' Association Journal, 15, 27-37.

Burrows-Hudson, S. (1995). Nephrology clinical outcomes part 1: Mortality, morbidity, adequacy of treatment, and quality of life. American Nephrology Nurses' Association Journal, 22, 113-121.

Campbell, A. , Converse, P. , & Rodgers, W. (1976). The quality of American life. New York: Russell Sage Foundation.

Chinn, P. L. , & Kramer, M. K. (1991). Theory and nursing: A systematic approach (3rd ed.). Chicago: Mosby-Year Book, Inc.

Dale, A. E. (1995). A research study exploring the patient's view of quality of life using the case study method. Journal of Advanced Nursing, 22, 1128-1134.

Dorfman, L. T. (1995). Health conditions and perceived quality of life in retirement. Health & Social Worker, 20, 192-199.

Evans, R. W. , Manninen, D. L. , Garrison, L. P. , Hart, L. G. , Blagg, C. R. , Gutman, R. A. , Hull, A. R. , & Lowrie, E. G. (1985). The quality of life of patients with end-stage renal disease. New England Journal of Medicine, 312, 553-559.

- Farquhar, M. (1995). Definitions of quality of life: a taxonomy. Journal of Advanced Nursing, 22, 502-508.
- Ferrans, C. E. (1990). Development of a quality of life index for patients with cancer. Oncology Nursing Forum, 17, 15-19.
- Ferrans, C. E. (1996). Development of a conceptual model of quality of life. Scholarly Inquiry for Nursing Practice: An International Journal, 10, 293-303.
- Ferrans, C. E. , & Powers, M. J. (1985). Quality of life index: Development and psychometric properties. Advances in Nursing Science, 8, 15-24.
- Ferrans, C. E. , & Powers, M. J. (1992). Psychometric assessment of the Quality of Life Index. Research in Nursing and Health, 15, 29-38.
- Ferrans, C. E. , & Powers, M. J. (1993). Quality of life of hemodialysis patients. American Nephrology Nurses' Association Journal, 20, 575-581.
- Ferrell, B. R. , Dow, K. H. , Leigh, S. , Ly, J. , & Gulasekaram, P. (1995). Quality of life in long-term cancer survivors. Oncology Nursing Forum, 22, 915-922.
- Ferrell, B. , Grant, M. , & Padilla, G. (1991). Experience of pain and perceptions of quality of life: Validation of a conceptual model. Hospice Journal, 7, 9-24.
- Ferrell, B. , Wisdom, C. , & Wenzl, C. (1989). QOL as an outcome variable in the management of cancer pain. Cancer, 63, 2321-2327.
- Kaplan, De-Nour, A. , & Shanan, J. (1980). Quality of life of dialysis and transplanted patients. Nephron, 25, 117-120.
- Mast, M. E. (1995). Definition and measurement of quality of life in oncology nursing research: Review and theoretical implications. Oncology Nursing Forum, 22, 957-963.

Meers, C. , Hopman, W. , Singer, M. , A. , MacKenzie, T. A. , Morton, A. R. , & McMurray, M. (1995). A comparison of patient, nurse, and physician assessment of health-related quality of life in end-stage renal disease. Dialysis & Transplantation, 24, 120-124.

Molzahn, A. E. , Northcott, H. C. , & Dossetor, J. B. (1997). Quality of life if individuals with end stage renal disease: Perceptions of patients, nurses, and physicians. American Nephrology Nurses' Association Journal, 24, 325-333.

Morgan, B. W. (1990). The relationship between chronological age and perceived quality of life of hemodialysis patients. American Nephrology Nurses' Association Journal. 17, 63-67.

Nissenson, A. R. , Fine, R. N. , & Gentile, D. E. (1995). Clinical Dialysis (3rd ed.). Norwalk, CT: Appleton & Lange.

Padilla, G. , Ferrell, B. , Grant, M. , & Rhiner, M. (1990). Defining the content domain of quality of life for cancer patients with pain. Cancer Nursing, 13, 108-115.

Polit, D. F. , & Hungler, B. P. (1995). Nursing Research. Principles and Methods (5th ed.). Philadelphia: J.B. Lippincott Company.

Sosa-Guerrero, S. , & Gomez, N. J. (1997). Dealing with end stage renal disease. American Journal of Nursing, 97, 44-50.

Wolcott, D. L. , Nissenson, A. R. , & Landsverk J. (1988). Quality of life in chronic dialysis patients: Factors unrelated to dialysis modality. General Hospital Psychiatry. 10, 267-277.0

## APPENDICES

## APPENDIX A

APPENDIX A

Demographic Data Form

I. How old are you? \_\_\_\_\_ (in years)

II. What is your sex?

1. \_\_\_\_\_ Male

2. \_\_\_\_\_ Female

III. What is your race? Are you:

1. \_\_\_\_\_ White

4. \_\_\_\_\_ Native American Indian

2. \_\_\_\_\_ Black

5. \_\_\_\_\_ Asian/Pacific Islander

3. \_\_\_\_\_ Hispanic

6. \_\_\_\_\_ Other

(please specify \_\_\_\_\_)

IV. What is your marital status?

1. \_\_\_\_\_ Single

4. \_\_\_\_\_ Separated

2. \_\_\_\_\_ Married

5. \_\_\_\_\_ Widowed

3. \_\_\_\_\_ Divorced

V. What is your employment status?

1. \_\_\_\_\_ Employed full time

4. \_\_\_\_\_ Disabled

2. \_\_\_\_\_ Employed part time

5. \_\_\_\_\_ Retired

3. \_\_\_\_\_ Unemployed

VI. How many years of school have you completed? \_\_\_\_\_ (in years)

VII. What was the range of your family's gross annual income last year?

1. \_\_\_\_\_ under \$5,000
2. \_\_\_\_\_ \$5,000 - 9,999
3. \_\_\_\_\_ \$10,000-14,999
4. \_\_\_\_\_ \$15,000 - 19,999
5. \_\_\_\_\_ \$20,000 - 24,999
6. \_\_\_\_\_ over \$25,000

VIII. How long have you been on hemodialysis? \_\_\_\_\_

IX. What caused your kidneys to fail?

1. \_\_\_\_\_ Diabetes
2. \_\_\_\_\_ High blood pressure
3. \_\_\_\_\_ Infection of the kidneys (glomerulonephritis)
4. \_\_\_\_\_ other (please specify \_\_\_\_\_)
5. \_\_\_\_\_ unsure of why kidneys failed

XI. Do you have any of the following medical conditions?

1. \_\_\_\_\_ Hypertension (high blood pressure)
2. \_\_\_\_\_ Diabetes
3. \_\_\_\_\_ Coronary artery disease
4. \_\_\_\_\_ Chronic obstructive pulmonary disease (COPD)
5. \_\_\_\_\_ Any other chronic medical condition

(Please specify \_\_\_\_\_)

## APPENDIX B



**Ferrans and Powers  
QUALITY OF LIFE INDEX©  
DIALYSIS VERSION**

**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.

<b>HOW SATISFIED ARE YOU WITH:</b>	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Dialysis treatment?	1	2	3	4	5	6
2. Your health?	1	2	3	4	5	6
3. The health care you are receiving?	1	2	3	4	5	6
4. Your physical independence?	1	2	3	4	5	6
5. The efforts made to increase your potential for a successful kidney transplant?	1	2	3	4	5	6
6. Your potential for getting off dialysis (for example, through a successful transplant or medical discovery)?	1	2	3	4	5	6
7. Your potential to live a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from others?	1	2	3	4	5	6

(Please Go To Next Page)

© Copyright 1984 Carol Estwing Ferrans and Marjorie J. Powers (Do not use without permission).

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
15. Your ability to meet family responsibilities?	1	2	3	4	5	6
16. Your usefulness to others?	1	2	3	4	5	6
17. The amount of stress or worries in your life?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your standard of living?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Your leisure time activities?	1	2	3	4	5	6
26. Your ability to travel on vacations?	1	2	3	4	5	6
27. Your potential for a happy old age/retirement?	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

(Please Go To Next Page)

© Copyright 1984 Carol Estwing Ferrans and Marjorie J. Powers (Do not use without permission).

**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.

<b>HOW IMPORTANT TO YOU IS:</b>	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Dialysis treatment?	1	2	3	4	5	6
2. Your health?	1	2	3	4	5	6
3. The health care you are receiving?	1	2	3	4	5	6
4. Your physical independence?	1	2	3	4	5	6
5. The efforts made to increase your potential for a successful kidney transplant?	1	2	3	4	5	6
6. Your potential for getting off dialysis (for example, through a successful transplant or medical discovery)?	1	2	3	4	5	6
7. Living a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from others?	1	2	3	4	5	6

(Please Go To Next Page)

© Copyright 1984 Carol Estwing Ferrans and Marjorie J. Powers (Do not use without permission).

	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
15. Your ability to meet family responsibilities?	1	2	3	4	5	6
16. Your usefulness to others?	1	2	3	4	5	6
17. The amount of stress or worries in your life?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your standard of living?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Your leisure time activities?	1	2	3	4	5	6
26. Your ability to travel on vacations?	1	2	3	4	5	6
27. Your potential for a happy old age/retirement?	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

© Copyright 1984 Carol Estwing Ferrans and Marjorie J. Powers (Do not use without permission).

## APPENDIX C

## Reliability and Validity of the Ferrans and Powers Quality of Life Index (QLI)

---

### Summary of Reliability Information

Internal Consistency Reliability Internal consistency reliability for the QLI (total scale) was supported by Cronbach's alphas ranging from .86 to .98 across 12 studies (Table 1). Cronbach's alphas for the four subscales have been published in six studies, which has provided support for internal consistency of the subscales (Table 2). Alphas ranged from .70 to .92 for the health and functioning subscale, from .77 to .89 for the social and economic subscale, and from .83 to .93 for the psychological/spiritual subscale. For the family subscale, alphas were acceptably high in five studies, ranging from .66 to .83.

Temporal (Stability) Reliability Support for temporal reliability was provided by test-retest correlations of .87 with a two-week interval and .81 with a one-month interval (Ferrans & Powers, 1985).

### Summary of Validity Information

Content Validity Content validity of the QLI was supported by the fact that items were based both on an extensive literature review of issues related to quality of life and on the reports of patients regarding the quality of their lives (Ferrans & Powers, 1985). Support for content validity also was provided by evaluation using the Content Validity Index (Oleson, 1990).

Construct Validity Convergent validity of the QLI was supported by strong correlations between the overall (total) QLI score and Campbell, Converse, and Rodgers' (1976) measure of life satisfaction ( $r = .61, .65, .75, .77, .80, .83, .93$ ) (Bliley & Ferrans, 1993; Ferrans & Powers, 1985; Ferrans & Powers, 1992; Anderson & Ferrans, 1997; Ferrans, 1990).

Further evidence for construct validity was provided by factor analysis. Factor analysis revealed four dimensions underlying the QLI: health and functioning, social and economic, psychological/spiritual, and family. The factor analytic solution explained 91% of the total variance. Factor analysis of the four primary factors revealed one higher order factor, which represented quality of life (Ferrans & Powers, 1992).

Construct validity also was supported using the contrasted groups approach. Subjects were divided into groups on the basis of self-reported levels of pain, depression, and success in coping with stress. Subjects who had less pain, less depression, or who were coping better with stress had significantly higher overall (total) QLI scores (Ferrans, 1990). The contrasted groups approach also was used to assess the construct validity of the social and economic subscale. It was found that those who had higher incomes had significantly higher quality of life scores on the social and economic subscale (Ferrans & Powers, 1992).

Table 1. Internal Consistency Reliability of the Ferrans and Powers Quality of Life Index (QLI): Total Scale

Population	Alpha	Study
<u>Cancer</u>		
Breast cancer patients		
Before treatment	.93	Hughes, 1993
After treatment (8 weeks)	.96	
Breast cancer survivors	.95	Ferrans, 1990
Melanoma patients	.95	Cowan, Young-Graham, & Cochrane, 1992
<u>Cardiac</u>		
Angioplasty patients		
Before PTCA	.86	Bliley & Ferrans, 1993
After PTCA (4-6 weeks)	.96	
Angioplasty and bypass surgery patients	.98	Papadantonaki, Stotts, & Paul, 1994
<u>End Stage Renal Disease</u>		
Hemodialysis and CAPD patients	.90	Ferrans & Powers, 1985
Hemodialysis patients	.93	Ferrans & Powers, 1992
<u>Other Illness Groups</u>		
Chronic fatigue syndrome	.93	Anderson & Ferrans, 1997
Multiple sclerosis patients	.87	Stuifbergen, 1995
Stroke survivors	.91	King, 1996
<u>General Population</u>		
Graduate students	.93	Ferrans & Powers, 1985
Korean-American women	.95	Kim & Rew, 1994

Table 2. Internal Consistency Reliability of the Ferrans and Powers Quality of Life Index (QLI): Subscales

Population	Health & Functioning Subscale	Social & Economic Subscale	Psychological/Spiritual Subscale	Family Subscale	Study
<u>Cancer</u>					
Breast cancer survivors	.90	.84	.93	.66	Ferrans, 1990
Melanoma patients	.92	.88	.85	.83	Cowan et al., 1992
<u>Cardiac</u>					
Angioplasty and bypass patients	.90	.89	.90	.79	Papapantonaki et al., 1994
<u>End-Stage Renal Disease</u>					
Hemodialysis patients	.87	.82	.90	.77	Ferrans & Powers, 1992
<u>Other Illness Groups</u>					
Chronic fatigue syndrome	.70	.84	.86	.70	Anderson & Ferrans, 1997
Stroke survivors	.86	.77	.83	.32	King, 1996



**Publications Reporting Reliability and Validity Information for the  
Ferrans and Powers Quality of Life Index (QLI)**

---

- Anderson, J. & Ferrans, C. (1997). The quality of life of persons with chronic fatigue syndrome. Journal of Nervous and Mental Disease, 136(6), 359-367
- Bliley, A. V., & Ferrans, C. (1993). Quality of life after angioplasty. Heart & Lung, 22(3), 193-199
- Cowan, M., Young-Graham, K., & Cochrane, B. (1992). Comparison of a theory of quality of life between myocardial infarction and malignant melanoma: A pilot study. Progress in Cardiovascular Nursing, 7(1), 18-28.
- Ferrans, C. (1990). Development of a quality of life index for patients with cancer. Oncology Nursing Forum, 17(3) suppl, 15-19.
- Ferrans, C. & Powers, M. (1985). Quality of Life Index: Development and psychometric properties. Advances in Nursing Science, 8, 15-24.
- Ferrans, C., & Powers, M. (1992). Psychometric assessment of the Quality of Life Index. Research in Nursing and Health, 15, 29-38
- Hicks, F., Larson, J., & Ferrans, C. (1992). Quality of life after liver transplantation. Research in Nursing and Health, 15, 111-119
- Hughes, K. K. (1993). Psychosocial and functional status of breast cancer patients. Cancer Nursing, 16(3), 222-229
- Kim S. & Rew, L. (1994). Ethnic identity, role integration, quality of life, and depression in Korean-American women. Archives of Psychiatric Nursing, 8(6), 348-356.
- King, R. (1996). Quality of life after stroke. Stroke, 27(9), 1468-1472.
- Oleson, M. (1990). Content validity of the Quality of Life Index. Applied Nursing Research, 3(3), 126-127.
- Papadantonaki, A., Stotts, N., & Paul, S. (1994). Comparison of quality of life before and after coronary artery bypass surgery and percutaneous transluminal angioplasty. Heart and Lung, 23(1), 45-52.
- Smith, C. (1994). A model of caregiving effectiveness for technologically dependent adults residing at home. Advances in Nursing Science, 17(2), 27-40
- Stuijbergen, A. (1995). Health-promoting behaviors and quality of life among individuals with multiple sclerosis. Scholarly Inquiry for Nursing Practice: An International Journal, 9(1), 31-50.

## APPENDIX D

## APPENDIX D

### Cover Letter

Chronic renal failure affects every aspect of your life, but each person is affected differently. The quality of your life is influenced by how you view what is happening to you right at this very moment. As a Master level student at Grand Valley State University I have had the chance to explore the idea of “quality of life”. I am interested in finding out how you as a hemodialysis patient view your quality of life as it is for you right now. The survey in this packet has been used to evaluate overall quality of life of hemodialysis patients such as yourself. The results of this survey will hopefully help your doctors and nurses understand what is important to you. As this is just a research project, I will not know the identity of anyone who completes this survey. My goal is to find out what the overall feelings of quality of life are within this dialysis unit.

I would like to thank you for your help in this research project. If you have any questions or concerns, please feel free to contact Tammy Bronson at 343-1555

## APPENDIX E

## APPENDIX E

### Informed Consent

Participation in this research project requires that you fill out the questionnaire to the best of your ability. The results of this questionnaire are for research purposes only and will not in any way affect the care you receive with Renal Care Group. Your identity will not be asked at any point within the questionnaire. If you choose not to participate in this project it will not affect your care or your treatment with Renal Care Group. You may ask questions at any time about the questionnaire during the week of the project. Your consent will be assumed if you complete and turn in the questionnaire to the labeled box at the front desk of the dialysis unit.

## APPENDIX F

Scoring Procedure for the  
Ferrans and Powers Quality of Life Index (QLI)\*

---

STEPS	CALCULATIONS
<u>Overall (total QLI Score)</u>	
1. Recode satisfaction scores	To center the scale on zero, subtract 3.5 from the satisfaction response for each item. (This will produce responses of -2.5, -1.5, -.5, +.5, +1.5, +2.5.)
2. Weight satisfaction responses with The paired importance responses.	Multiply the recoded satisfaction response By the raw importance response for each Pair of satisfaction and importance items.
3. Obtain preliminary sum for the overall (total) score.	Add together the weighted responses Obtained in step 2 for all of the items.
4. Obtain final overall (total) QLI score.	To prevent bias due to missing data, divide Each sum obtained in step 3 by the number of items answered by that individual. (At this point the possible range for scores is -15 to +15.) Next, to eliminate negative numbers for the final score, add 15 to every score. This will produce the final overall (total) QLI score. (Possible range for the final scores = 0 to 30).

Subscale Scores

The same steps are used to calculate subscale scores as total scores The only difference is that the calculations are performed using subsets of items, rather than on all of the items.

1. Recode satisfaction scores	To center the scale on zero, subtract 3.5 from the satisfaction response for each item. (This will produce responses of -2.5, -1.5, -.5, +.5, +1.5, +2.5.) This is exactly the same step as #1 above.
-------------------------------	---

- |    |   |  |
|----|---|--|
| 2. | Weight satisfaction responses with the paired importance responses. | Multiply the recoded satisfaction response By the raw importance response for each pair of satisfaction and importance items. This is exactly the same step as #2 above.   |
| 3. | Obtain preliminary sum for the subscale score.                      | Add together the weighted responses Obtained in step 2 <u>for the items that compose the subscale.</u>   |
| 4. | Obtain the final subscale score.                                    | To prevent bias due to missing data, divide each sum obtained in step 3 by the number of items answered in that subscale for that individual. (At this point the possible range for scores is -15 to +15. This is the possible range for all four of the subscales and for the overall (total) score. The possible range is the same for all five scores even though they have different numbers of items, because we have divided the preliminary sum by the number of items answered for each one.) Next, to eliminate negative numbers for the final score, add 15 to every score. It is always the number 15 that is added, regardless of which subscale score is being calculated. This will produce the final subscale score. (Possible range for the final scores = 0 to 30.) the possible range for the final scores is the same for all four subscales and for the overall (total) score. |

- 
- A computer program that performs the above calculations using SAS is included in the packet of materials sent with this instruction sheet.



## **SUBSCALES OF THE QUALITY OF LIFE INDEX (QLI) – DIALYSIS VERSION**

---

Items listed below are from both Part 1 (Satisfaction) and Part 2 (Importance). For example, “2. Own health” refers to question #2 in part 1 and question #2 in Part 2.

### Health and functioning subscale

1. dialysis treatment
2. own health
3. health care
4. physical independence
5. transplant
6. get off dialysis
7. long life
12. sex life
15. family responsibilities
16. usefulness to others
17. stress
25. leisure
26. travel
27. retirement

### Social and economic subscale

13. friends
14. emotional support
18. home
19. neighborhood
20. standard of living
- 21/22. Job/unemployment
23. education
24. financial independence

### Psychological/spiritual subscale

28. peace of mind
29. faith in God
31. goals
32. happiness
33. personal appearance
34. self

### Family subscale

8. family health
9. children
10. family happiness
11. spouse

## APPENDIX G

Department of Medical-Surgical Nursing (M/C 802)  
College of Nursing  
845 South Damen Avenue, 7th Floor  
Chicago, Illinois 60612-7350  
(312) 996-7900

March 13, 1998

Ms. Tammy Bronson  
3527 Madison Street  
Kalamazoo, MI 49008


Dear Ms. Bronson:

I am happy to give you permission to use my conceptual framework for quality of life for your thesis. I have enclosed a recent publication regarding the development of the framework.

I wish you much success with your graduate studies.

Sincerely,

C

  
Carol Estwing Ferrans, PhD, RN, FAAN  
Associate Professor

Department of Medical-Surgical Nursing (M/C 802)  
College of Nursing  
845 South Damen Avenue, 7th Floor  
Chicago, Illinois 60612-7350  
(312) 996-7900

October 16, 1997

Ms. Tammy Bronson  
3527 Madison Street  
Kalamazoo, MI 49008


Dear Ms. Bronson:

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 the subscale scores and overall scores.

At the present time 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 a photocopy of all publications of your findings using the QLI. I then will add your publication(s) to the list that I send out to persons who request permission to use the QLI.

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  
Associate Professor

## APPENDIX H



GRAND VALLEY  
STATE UNIVERSITY

I CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

June 24, 1998

Tammy Bronson  
3527 Madison St.  
Kalamazoo, MI 49008

Dear Tammy:

The Human Research Review Committee of Grand Valley State University is charged to examine proposals with respect to protection of human subjects. The Committee has considered your proposal, "*Quality of Life of the Hemodialysis Patient*", and is satisfied that you have complied with the intent of the regulations published in the Federal Register 46 (16): 8386-8392, January 26, 1981.

Sincerely,

A black rectangular box redacting the signature of Robert Hendersen.

Robert Hendersen, Acting Chair  
Human Research Review Committee